



Neurobehavioral Issues of Traumatic Brain Injury: An Introduction

Prepared by the
National Association of State Head Injury Administrators'
Neurobehavioral Health Committee

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The National Association of State Head Injury Administrators assists State government in promoting partnerships and building systems to meet the needs of individuals with brain injuries and their families.

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Executive Summary

In the United States, traumatic brain injury (TBI) is a major public health concern and the leading cause of death and disability among children and young adults. Injuries to the brain are characterized by a) high cost of hospitalization and rehabilitative treatment, b) permanence of the resulting disability, and c) more frequent occurrence in children and youth.

TBI is not a single, unified disorder with a clear, consistent set of symptoms but a multi-dimensional syndrome. The cognitive, social, emotional and behavioral issues that frequently arise are often cited as the greatest impediment to the individual's reintegration into the home, community, and workplace. This constellation of symptoms is often referred to as the neurobehavioral cluster.

The purpose of this document is to provide State Agency administrators and providers (often focused on other areas of disability) with an introduction to TBI-related neurobehavioral health issues and to offer a glimpse at what some States are doing to address these issues from a systems perspective.

Part I and Part II provide an introduction to TBI and its neurobehavioral issues, respectively. Part III discusses how interdisciplinary treatment teams develop effective treatment plans. Part IV describes how certain professions play key roles in neurobehavioral assessment and intervention. Part V shares several States' successes and lessons learned around their systems development initiatives. Part VI instructs professionals how to work effectively within the mental health, substance abuse, and criminal justice systems.

The committee offers these recommendations to further neurobehavioral systems development:

1. Increased identification and awareness of neurobehavioral residuals is needed.
2. Collaboration between all constituents is a requirement...not just a nice idea.
3. Every single support dollar available is needed to address the TBI problem.
4. Professionals need to be responsive, work as a team, and advocate to identify cohesive approaches at both individual and systems levels.
5. Collaborative systems of service and support must be strengthened by real technological innovations that contribute to functional outcome in the lives of persons with TBI.
6. Applicable, detailed, and creative protocols are needed to orient and promote relevant practices within systems.
7. A new, innovative, and pervasive plan is needed to promote public/legislative awareness of the long-term consequences of brain injury.

Part I: Background

In the United States, traumatic brain injury (TBI) is a major public health concern and the leading cause of death and disability among children and young adults. Injuries to the brain are characterized by a) high cost of hospitalization and rehabilitative treatment, b) permanence of the resulting disability, and c) more frequent occurrence in children and youth.

TBI is not a single, unified disorder with a clear, consistent set of symptoms but a multi-dimensional syndrome affecting a wide variety of cognitive, physical, emotional, social, and behavioral functions. Brain injuries affect each individual uniquely, with consequences dependent on a multitude of factors such as severity and location of injury, age, past history of brain injuries, substance use, and previous abilities and functioning.

While the medical and physical consequences of a brain injury are often devastating, the cognitive, social, emotional and behavioral issues that frequently arise can influence lives just as dramatically. In fact, these issues are often cited as the greatest impediment to the individual's reintegration into the home, community, and workplace. This constellation of symptoms is often referred to as the neurobehavioral cluster. Early stages of brain injury rehabilitation are likely to focus on medical and physical recovery. It is often the longer term, more subtle and difficult to identify/treat neurobehavioral issues that disrupt individual functioning, family relations, vocational participation, and quality of life.

Although many human service organizations (HSOs) attempt to design effective home and community-based services and supports for individuals with brain injury, all too often many issues, including neurobehavioral issues, are misunderstood and/or misdiagnosed, leading to the provision of inappropriate services. State HSOs are likely to become involved after other efforts to provide needed services fail. They prevent ongoing or reoccurring use of specialized environments (e.g., psychiatric hospitals, nursing homes, developmental centers, and correctional facilities) or programs that are unsuccessful at addressing possible risks.

So, what is the role of State government in this concern? In all aspects of our lives, the role of the State or Federal government has been to provide infrastructure. State and Federal governments build roads and bridges. They maintain schools and hospitals. They perform these kinds of tasks for the common good of the society and the individuals within the society. This helps individuals live and work together safely. For individuals with TBI, there should be no more or no fewer protections provided. The role of the State and Federal government is to establish systems that ensure all our citizens, especially the most vulnerable, are able to access and thrive in their communities. In this regard, the National Association of State Head Injury Administrators (NASHIA) is in full agreement with key components of President Bush's "New Freedom Initiative" aimed at reducing barriers to people with disabilities. These goals include increasing opportunities to learn and develop skills, choose where to live, and participate in community life.

The current state of services for neurobehavioral health issues reveals a wide variety of service delivery mechanisms and approaches. While there is no universally accepted treatment approach, there is a clear set of values that appear in all service programs. In accordance with these values, the goal for all services is to be:

- designed to meet the needs of the consumer;
- community-based based and flexible, changing as people's needs change;
- responsive to people's unique concerns, enabling them and their families to make informed decisions;
- available, adequate, and timely; and
- based on evidence-based practices.

Purpose

The purpose of this document is to provide State Agency administrators and providers (often focused on other areas of disability) with an introduction to TBI-related neurobehavioral health issues and to offer a glimpse at what some States are doing to address these issues from a systems perspective.

Definition

A traumatic brain injury is an injury to the head arising from 1) blunt or penetrating trauma, such as a fall or gunshot wound, or 2) acceleration-deceleration forces, such as a motor vehicle accident or shaken baby syndrome. A TBI is one of two subtypes of acquired brain injury. The other subtype, non-traumatic brain injury, is a result of a medical condition, including cerebrovascular disorders (e.g., stroke), neurologic diseases (e.g., multiple sclerosis), brain tumors, and toxic chemical or drug reactions. Loss of oxygen to the brain (e.g., anoxia) may occur in either of these subtypes. Regardless of what caused the brain injury, the person experiencing the injury may present with physical or cognitive symptoms that may lead to behavioral changes and some level of long-term disability.

Prevalence

According to the Centers for Disease Control and Prevention (CDC), it is estimated that of the 1.4 million people who sustain a TBI each year in the United States: 50,000 die, 235,000 are hospitalized, and 1.1 million are treated and released from hospital emergency departments. Of those who survive, an estimated 80,000 to 90,000 people will experience the onset of long-term disability as a result of TBI.¹ The number of individuals in the United States currently with a long-term or lifelong need for help to perform activities of daily living as a result of TBI is estimated to be at least 5.3 million.²

¹ Langlois JA, Rutland-Brown W, Thomas KE. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta (GA): Centers for Disease Control and Prevention, NCIPC; 2004.

² Thurman D, Alverson C, Dunn K, Guerrero J, Sniezek J. Traumatic brain injury in the United States: a public health perspective. *Journal of Head Trauma Rehabilitation* 1999;14(6):602-15.

In the Children's Health Act of 2000 (Public Law 106-310), Congress recognized that the estimated figure of 5.3 million is an undercount of the actual number of individuals who have a TBI-related disability. This is because the figure is based on the number of individuals discharged from a hospital following an overnight stay. This does not include individuals seen in emergency departments who are not admitted. It also does not include individuals who have visited physicians' offices, or individuals who have not sought even treatment. It does not include those persons living with other acquired brain injuries (subtype 2). Finally, the number presumably has been increasing annually at a rate of 80,000-90,000 per year since this estimate was published.

General consequences

In 1998, the National Institutes of Health sponsored a Consensus Development Conference on the Rehabilitation of Persons with TBI. The following excerpts from the post-conference report offer a comprehensive description of the consequences of TBI:

Rarely are the consequences limited to one set of symptoms, clearly delineated impairments, or a disability that affects only one part of a person's life. Rather, the consequences of TBI often influence human functions along a continuum from altered physiological functions of cells through neurological and psychological impairments, to medical problems and disabilities that affect the individual with TBI, as well as the family, friends, community, and society in general. When other, more urgent medical problems are apparent at onset, mild TBI may be masked, even though it can result in impairments. In many cases, the consequences of TBI endure in original or altered forms across the lifespan, with new problems likely to occur as a result of new challenges and the aging process.

The neurological consequences of TBI are many and complex, occurring throughout the neural axis. Any sensory, motor, and autonomic function may be compromised. Most of these complications are apparent within the first days or months following injury, depending on the severity of initial trauma. Some long-term sequelae include a variety of movement disorders, seizures, headaches, ambient visual deficits, and sleep disorders. Non-neurological medical complications include, but are certainly not limited to, pulmonary, metabolic, nutritional, gastrointestinal, musculoskeletal, and dermatologic problems.

The cognitive consequences of TBI are similarly broad. All of these consequences can occur singly or in combinations and are variable in terms of their effects on individuals; furthermore, they change in severity and presentation over time. In combination, they produce a myriad of functional problems. Some of the most persistent problems include memory impairment and difficulties in attention and

concentration. Deficits in language use and visual perception are common, but often unrecognized. Frontal lobe functions, such as the executive skills of problem-solving, abstract reasoning, insight, judgment, planning, information processing, and organization, are vulnerable to TBI.

Common behavioral deficits include decreased ability to initiate responses, verbal and physical aggression, agitation, learning difficulties, shallow self-awareness, altered sexual functioning, impulsivity, and social disinhibition. Mood disorders, personality changes, altered emotional control, depression, and anxiety are also prevalent after TBI.

Social consequences of mild, moderate, and severe TBI are many and serious, including increased risk of suicide, divorce, chronic unemployment, economic strain, and substance abuse. These consequences are tragic to individuals and families and place additional burdens on social service agencies, law enforcement, and the courts. As individuals with TBI attempt to resume their usual daily activities, the environment places increasing demands on them, uncovering additional psychosocial consequences. For example, executive dysfunction may become obvious only in the workplace; behavioral changes affecting interpersonal relationships may appear after leaving inpatient care. Spiraling adverse consequences of TBI may become apparent not only for persons with TBI but also for their significant others. Family members report depression, social isolation, and anger. Overall family functioning and relationships are disrupted. Such consequences may continue and, in some instances, worsen with age.

Children with TBI have their own set of consequences. Interactions of physical, cognitive, and behavioral sequelae interfere with the task of new learning. The effect of early TBI may not become apparent until later in the child's development, although there is little explicit literature on the developmental consequences of TBI in infants. There may be a poor fit between the needs of children with TBI and the typical school educational programs. Children with TBI also may have difficulties with peers due to cognitive processing, behavioral problems, or difficulty comprehending social cues. Parents are faced with significant parenting challenges, including coping with changed academic aspirations and family goals.

TBI in adolescents has been largely unstudied. It is unclear, therefore, whether the consequences they face are best described by the literature pertaining to adults or children.³

³ Rehabilitation of Persons With Traumatic Brain Injury. NIH Consensus Statement Online 1998 Oct 26-28; [<http://consensus.nih.gov/1998/1998TraumaticBrainInjury109html.htm>, 2006 Mar 30];16(1): 1-41.

Part II: Orienting to Neurobehavioral Issues

Cognitive, physical, and perceptual changes may follow a traumatic brain injury, affecting how a person experiences the world and interprets events. These changes are likely to affect how the person interacts with others and responds behaviorally.

Behavioral issues often constitute the biggest challenge for the family, community, and others who become involved with an individual after a brain injury. These issues can be characterized in a number of different ways. At the neurological level, particular areas of the brain may be characterized as contributing to behavioral issues (e.g., frontal lobe injury is often associated with behavioral disturbance). Or, particular cognitive or perceptual functions may be connected with certain behaviors (e.g., problems with memory, concentration, attention, or language).

As time passes following an injury and assessment continues, it is likely that behavioral issues will be represented in progressively more specific ways. For example, behavioral problems are frequently characterized as being the result of problems with initiation, agitation, learning difficulties, self-awareness, judgment, planning, organization, problem solving, impulse control, and social disinhibition. Health care providers might consider these more descriptive “executive functions” in their attempt to interact, understand, treat, and provide more targeted assistance.

At another descriptive level, behavioral issues following brain injury are often characterized with action verbs including shouts, resists, disrupts, cries, uses (substances), cusses, threatens, or aggresses. Typically, it is these “unwanted” behavioral ramifications of neurological involvement and cognitive impairment that produce the biggest concerns for families and communities, and bring the individual to the attention of professionals or service agencies. There can be a great deal of variability in the intensity of unwanted behavior, from an awkward social comment to potentially dangerous property destruction, self injury, or aggression.

Many individuals who exhibit intense, or potentially risky or challenging behavior following a brain injury are treated by professionals who have not been trained in brain injury and in settings not designed to address brain injury. This can occur because many rehabilitation programs and families are not well-equipped to address the risks that some individuals pose and because other settings are more typically associated with mental health/psychiatric behaviors. It may also occur because the behaviors are not viewed as being related to a brain injury or because specific brain injury services and supports are not yet well-developed. In either case, the potential pitfalls are clear. When persons with brain injury are served by systems not sensitive to the unique issues they face, there is increased chance that the relation between the brain injury and the behavior will become blurred, disregarded, or sometimes completely lost.

It is always difficult to communicate in general ways about any group of individuals, let alone make comparisons between groups. Nevertheless, given the need for increased education about brain injury, such generalizations probably cannot be avoided.

Initially, it is especially important for those who assist persons with brain injury to recognize behaviors that are a direct result of the injury. We need to grasp both the neurological impact of the injury (e.g., what part of the brain was affected) and *who the person was* prior to the injury, in order to better understand what has changed. For example, a person who regularly engaged in street fighting and substance use prior to a brain injury is more likely to be aggressive and seek substances following an injury. Though the injury may exacerbate or change characteristics of these behaviors, they may or may not be related to the injury. We need to look much differently at the situation of a person who suddenly becomes aggressive or seeks substances following frontal lobe brain injury.

Some brain – behavior relationships

Recognizing the relationship between physical insults to the brain and a resulting behavior change has very practical significance when we interact with an individual. Foremost, we need to recognize that the behavior the person is displaying may be no more controllable (or, in some cases, treatable) than the physical residuals of their injury. Persons who do not appreciate this relationship can often be heard giving complex verbal instructions or corrections to individuals they serve. Then, they become frustrated when the individuals do not follow their directions. Unfortunately, verbal instructions/corrections are unlikely to have any impact on the neurological and biochemical mechanisms that affect the behavior of individuals with brain injury. In some cases, they can even make a bad situation worse (e.g., when problem behavior is the result of verbal processing difficulties). If we expect to influence a change in behavior of individuals—behavior that can be as basic as relearning how to walk—we will need a more systematic approach to help the individual compensate for the neurological impairment, one step at a time. We also need to recognize that our efforts may not always be successful and the individual may need ongoing accommodation or support.

As we continue to orient to neurobehavioral issues in serving and treating individuals with TBI, we will also need greater understanding of specific “brain-behavior” relationships in order to design sensitive interventions. An extensive look at these relationships is beyond the scope of this document. Some brief examples, however, may help demonstrate how the relationship between neurology, cognitive residuals, and behavior can impact how we intervene in certain situations.

Brain injury often produces intense confusion (e.g., sometimes as a result of sensory overload) that may be lasting or *situational* and can lead to vivid avoidance of certain situations or an array of highly emotional behavior. Failing to recognize that an individual is intensely confused can lead those attempting to provide assistance to focus only on the unwanted behavior rather than the *situation* that produced it. In general, this sort of approach is unlikely to be very successful in changing behavior because it does not necessarily help the individual become less confused when the situation again arises.

Similarly, a person with a brain injury can experience lasting or situational disorientation (e.g., similar to how travelers often feel waking up in a strange place). Particularly early

in post-injury, helpers may want to take extreme measures to keep disoriented persons away from situations posing risks for them (e.g., open areas of a hospital unit, the neighborhood, city streets, etc.). At the same time, we also need to consider what we can do to help the individual orient more effectively on their own in increasingly complex situations. Considering that a problem behavior may be the result of not understanding a situation can change the helper's role from one of behavior manager to interpreter. It can also help protect against the cruel use of unnecessary restrictiveness or isolation as a means of creating a distraction free or low-stimulation environment.

Physical difficulties (e.g., limited mobility, pain, spasticity, etc.) and the emotional impact of these difficulties can also be at the root of behavioral disturbances after brain injury. For example, it should be no surprise that behavioral issues after brain injury often show up first during physical rehabilitation. Sometimes, this can be the result of an individual experiencing pain without having any other means to communicate their dissatisfaction with the person producing it. Many physical therapists have learned that, rather than discharging persons from therapy due to behavioral resistance, part of their work needs to be geared toward teaching communicative alternatives to the problem behavior. In fact, their attention to the physical, communicative, and behavioral aspects of the injury is a very good example of what we call "transdisciplinary" rehabilitation. Finally, perceptual difficulties that result from brain injury can contribute to the emergence of all sorts of unwanted behaviors. If a person has difficulty processing visual or spoken information, they may behave in a way that says they do not care, that they are not motivated, or that they are resistant to help. If a person does not perceive the impact of his or her behavior on others, then he or she may experience difficulties developing and maintaining relationships. If a person has difficulty interpreting verbal input, then it should be expected that they would fail to initiate, miss appointments, or have trouble in social exchange.

Providers should consider that learning does not stop following brain injury. And some things that people learn may not necessarily be viewed as being in their best interests. For example, an individual who experiences withdrawal of a painful therapy or a challenging expectation, following their display of agitated or aggressive behavior, may be more likely to repeat such behavior in future difficult situations. While the individual may be neurologically predisposed to behaving aggressively (e.g., due to cognitive impairments), providers also need to be sensitive to the contribution of post-injury experience and learning. We must be careful not to allow unwanted behavior to produce desired outcome (e.g., be rewarded), but in many cases it may.

Dual or multi-diagnoses

As noted earlier, understanding the relation between pre-injury functioning and post-injury behavior can be a very important issue for service providers. In many cases, a pre-existing learning difficulty, attention disorder, substance abuse problem, or psychiatric disturbance may have preceded the brain injury. When this is the case, it may further complicate our interpretation of difficulties an individual is experiencing (e.g., withdrawing from nicotine or cocaine during rehabilitation), the assistance that is

provided (e.g., distinguishing between delusional and disoriented behavior), and, most importantly, the individual's recovery. Concern about pre-existing conditions may be particularly important in assessment and intervention with children and adolescents. Their difficulties can have a huge impact on successful reintegration into the family and school.

While it is important to consider the relative and combined influence of pre-existing conditions and brain injury, another important issue pertains to the assessment and *interpretation* of behavior following brain injury. There has been longstanding concern among many neurobehavioral rehabilitation providers that the cognitive-behavioral effects of brain injury are frequently over interpreted as psychiatric symptomatology. This should come as no surprise, particularly when individuals who have experienced dramatic effects of brain injury are often treated in psychiatric or medical/nursing settings (due to the potentially dangerous behaviors they exhibit).

A provider's orientation to behavioral issues after brain injury has important implications on where and how he or she serves an individual. It is especially important that the treating team have all the benefit of medical, psychiatric, neuropsychological, and behavioral assessment when attempting to determine the most useful intervention approach. Not including all of these perspectives can result in a host of problems, such as:

- use of ineffective or harmful medications that may impede cognitive functioning;
- over-reliance on complex psychological/cognitive interventions for which the individual is not prepared; and
- excessive use of corrective or restrictive "behavior management" or simplistic behavioral interventions that are insensitive to the neurological, cognitive, or emotional aspects of the injury.

Many persons who experience brain injury have pre-existing conditions that may impact their recovery (e.g., learning disabilities, psychiatric disorders, etc.). Others will experience onset of learning difficulties and psychiatric disturbance following their injuries. Some compelling statistics supporting these statements are offered by Francesca LaVecchia, Ph.D., and Thomas W. McAllister, M.D., in the National Association of State Head Injury Administrators' three-part *Neurobehavioral Issues* Radiocast series.⁴ As State program administrators and service providers, one of our most important jobs is to help insure that individuals with these kinds of problems have access to the most relevant professional assistance likely to produce the most meaningful outcomes in their lives.

⁴ Order a copy online at: <http://www.nashia.org>. The price for the three-part *Neurobehavioral Issues* Radiocast series on CD-ROM and CEUs is \$75.00.

Part III: Organizing the Treatment Team

While brain injury can impact a wide variety of human functions, we are focusing on the neurobehavioral issues in this document. Considering that no model currently exists for assessing and treating brain injury-related neurobehavioral issues, guidelines are needed to assist us in identifying and accessing appropriate assistance. Professionals from a variety of service and support systems (e.g., Mental Health, Mental Retardation/Developmental Disabilities, and Chemical Dependency) may frequently interact with persons with brain injury. Unless they are aware of the neurobehavioral issues associated with TBI, their efforts may lead to development of ineffective treatment plans. Furthermore, while medications may be used to address a variety of neurobehavioral issues, careful monitoring is necessary to ensure they do not negatively impact cognitive, physical, and perceptual functioning. Simply put, you must get to the source of medical, cognitive, and behavioral symptoms before developing the treatment plan.

Some acknowledged best practices in assessment include:

- An examination of the person's pre-injury lifestyle that includes input from the individual with brain injury, his or her family members, friends, and coworkers.
- Evaluations by a neurologist, neuropsychologist, neuropsychiatrist, and physiatrist to assess the impact of the injury on functional abilities and the need for services and supports.
- Evaluations by other professionals such as physical, occupational, behavioral, and speech/language therapists, a vocational rehabilitation counselor, and social worker.
- Use of an interdisciplinary team to develop a treatment plan which may include an array of services, such as:

Psychological/Behavioral	Specialized Medical Equipment
Acute/Post-Acute Inpatient Treatment	Case Management
Consumer-Directed Attendant Care	Respite
Family Counseling and Training	Supported Community Living
Home and Vehicle Modifications	Supported Employment
Medical Monitoring and Treatment	Transportation
Personal Emergency Response System	Prevocational
Physical, Occupational, or Speech Therapy	Personal Care
Residential Habilitation/Rehabilitation	Adult Day Care
- Provision of a supportive environment that teaches new skills and strategies to assist the individual in overcoming lost skills and developing independence, being careful *not* to underestimate the person's current knowledge base/skill set or take into account their individual clinical needs.

Tools and techniques critical to proper identification of TBI

Brain injury awareness and identification is critical since many persons with TBI will need access to behavioral health services. In many cases, these individuals will present with various diagnoses and not have a documented brain injury diagnosis. In situations

where individual behavior suggests the possibility of brain injury, screening for brain injury is absolutely necessary. This may require partnering or consulting with colleagues in the brain injury field to facilitate the provision of effective interventions and supports.

Professionals: their roles and practices in assessing and treating TBI

The involvement of a variety of professionals is often necessary to begin meeting the needs of individuals with neurobehavioral health issues. However, it is most important to involve the individual with TBI and, when possible, their family members. Too many specialized behavioral treatment environments spend far too much time assessing and designing behavioral interventions and far too little time including the recipient of their services in the design and implementation of their own treatment. In many ways, it is no longer about having a professional team design and implementing a behavior management plan. It is more about designing an inclusive team that assists the individual in intervening more effectively on his or her own behalf.

In many situations, family members either receive too little or too complex information from providers on their roles in the rehabilitation process. Family members have a natural tendency to withdraw or avoid situations where they either feel frightened or ill-equipped to contribute in a safe and meaningful way. But not involving family members as a vital part of the treatment team can have dramatic effects on the outcome. Translating complex terminology into language that can be understood and used by the family may be the most important way that the team can facilitate family involvement.

A number of different human service professionals may need to participate in the assessment and treatment of a person with TBI. Collaboration between disciplines is essential in order to affect the best outcome. However, it is important that a professional's experience in assessing and treating individuals with non-TBI- related, neurobehavioral health issues **not** have a major influence on his or her, or your, recommendations.

In addition to the individual and their family members, here's a list of professionals that play a critical role on the treatment team:

Behavior Analyst	Occupational Therapist
Direct Care Staff	Physiatrist
Neurologist	Physical Therapist
Neuropsychiatrist	Social Worker/Case Manager
Neuropsychologist	Speech/Language Pathologist
Nurse	Vocational Rehabilitation Counselor

The neurologist, neuropsychologist, neuropsychiatrist, and physiatrist give the first level of assessment to determine the impact of injury on functional abilities. Assessment should include proper evaluation, treatment recommendations, and referral to other specialties. The role of these four specialists is defined below. A glossary of other specialties (listed above) is included as Appendix D.

Neurologist. A neurologist is a medical doctor or osteopath trained in the diagnosis and treatment of nervous system disorders, including diseases of the brain, spinal cord, nerves, and muscles. Neurologists perform examinations of the nerves in the head and neck, muscle strength and movement, balance, ambulation, and reflexes. They also test for sensation, memory, speech, language, and other cognitive abilities.

Neuropsychologist/Psychologist. A clinical neuropsychologist is a professional within the field of psychology with special expertise in the applied science of brain-behavior relationships. Clinical neuropsychologists use this expertise in the assessment, diagnosis, treatment, and/or rehabilitation of people of all ages. He or she evaluates patients' neurocognitive, behavioral, and emotional strengths and weaknesses and their relationship to normal and abnormal central nervous system functioning. They also assist with planning and implementing intervention strategies to improve functioning. If the services of a neuropsychologist are not available, a psychologist can be contacted to furnish diagnostic, assessment, preventive, and therapeutic services focusing on helping individuals resolve problems.

Neuropsychiatrist/Psychiatrist. Neuropsychiatry is the connecting area between psychiatry and neurology. This is a specialized medical discipline that addresses the behavioral or psychological difficulties associated with known or suspected neurological conditions. Neuropsychiatrists are trained to evaluate neurobehavioral complications, including problems with mood regulation, impulse control, irritability or anger management, and psychosis. Another area of their expertise is the behavioral effects of medications. When the services of a neuropsychiatrist are not available, a psychiatrist can be consulted to assist with the diagnosis and treatment of emotional issues or bona fide mental illness following brain injury.

Physiatrist. A physiatrist is a medical doctor who focuses on restoring physical function. He or she is a specialist in diagnosing and treating in three major areas:

- musculoskeletal injuries and pain syndromes;
- electrodiagnostic medicine; and
- rehabilitation of patients with severe impairments resulting from catastrophic events or neurologic disorders.⁵

⁵ Association of Academic Physiatrists, www.physiatry.org.

Part IV: Neurobehavioral Assessment and Intervention

Certain professions are likely to play key roles in the assessment and design of formal interventions for persons with TBI-related behaviors. We will focus here on a few, not intending to minimize the contribution of others. It was the desire of NASHIA's Neurobehavioral Health Committee to solicit the expertise of experienced practitioners. The information presented here is written by different contributing authors for each discipline represented.

Neurology *By Colin Hall, M.D.*

A neurological evaluation of individuals with traumatic brain injury usually serves one of two purposes. The first is to identify acute measures that may stabilize or reverse brain damage, such as the administration of medication or surgical intervention, at and around the time of the injury. Some neurological studies performed at this time may also provide information on the likelihood of immediate survival and, less reliably, the degree of long-term disability. The second is to assess residual dysfunction and to aid in the design of rehabilitation strategies during and/or after the convalescent period.

In the acute stages, the bedside neurological examination by a trained clinician remains essential. In all but the most minimal trauma, the individual should also have some form of imaging study. Plain x-ray of the skull is used less commonly than previously, because of the greater efficacy of computer-assisted tomography (CT) or magnetic resonance imaging (MRI) scanning. CT scans are generally the study of choice. The head is positioned in a halo-shaped device. X-ray images of the head are taken from various points in the halo, and then fed into a computer to reconstruct images of the brain. Taking only a few minutes, the CT scan is particularly helpful in identifying blood clots in or around the brain and the need for acute surgical intervention. It can also identify brain swelling, foreign objects such as bullet fragments, and infections resulting from penetrating wounds. CT may also be helpful in establishing brain death. Recent developments in CT technology make it possible to compare the volume and rate of blood flow in different areas of the brain, and this is likely to become another helpful tool in assessment.

Although an MRI allows for more sophisticated evaluation of the brain and may identify nerve cell damage too subtle to be seen on a CT, for many MRI is more difficult to obtain on an immediate basis, and is also considerably more expensive. Instead of x-rays, the MRI machine delivers a magnetic pulse that causes the molecules in the brain to vibrate. Different tissues vibrate differently and the computer uses this to display again a detailed image of the brain. The MRI scanner is a cylindrical machine, which encases the upper body with only a few inches of free space above and at the sides. The patient must remain completely still for a few minutes. Some patients find this very claustrophobic and may require sedation. With many MRI machines, the patient must weigh less than 300 pounds to be able to fit into the machine.

For electroencephalography (EEG), electrodes are placed over standardized areas of the scalp to record the electrical impulses of nerve cells in the brain, in the same way that electrocardiography records the electrical impulses of heart muscle. The greatest value of EEG in the acute stages of head trauma is to identify epileptic seizures resulting from the injury. These can be particularly difficult to diagnose in the already unconscious patient. The study takes from 20 to 60 minutes to perform and can be done in the laboratory or at the bedside. At times, it is helpful to perform video EEG recording where the EEG is recorded continuously over hours or days. A camera records the patient's motor activity, looking for evidence of seizures. EEG is also used in identifying brain death.

In the acute stages a clinician may also present stimuli, such as repetitive sounds or visual images, known as "evoked potentials" to the patient in combination with the EEG to evaluate prognosis. Brainstem auditory evoked potentials have been studied in depth as a tool in acute brain injury, but have limited clinical value.

In the weeks or months after the acute phase of injury—when the patient's status has stabilized—neurological assessment may give valuable information for long-term prognosis and optimizing treatment strategies. CT and MRI scanning at this stage may be helpful in identifying the degree of structural damage in the brain, which has some correlation with functional outcomes. Rarely these technologies may identify surgically remediable complications of trauma, such as unexpected blood collections like subdural hematoma or post-traumatic hydrocephalus. Recent adaptations of MRI are being studied for their potential value in assessing and treating traumatic brain injury but are not yet in general clinical use. These adaptations include a) magnetic resonance spectroscopy (evaluates chemical changes in the brain), b) diffusion tensor imaging (displays nerve tract damage), and c) functional MRI (identifies individual areas of brain activity). EEG and video EEG monitoring may be necessary for evaluation of seizures, particularly in differentiating them from behavioral abnormalities related to brain damage.

Positron emission tomography (PET) scan is performed by injecting a substance with a very low level of radioactive activity into the blood, and then measuring its uptake in different areas of the brain. While this may prove of great value in identifying localization of lesions and potential for recovery, the technology is not yet widely available and its usefulness outside the research setting is not fully established.

Neuropsychiatry

By Thomas McAllister, M.D.

There are three broad categories of indicators that the neurobehavioral sequelae of TBI should be a focus of treatment. The first and perhaps most obvious is awareness on the part of the individual with TBI or his or her family/caregiver that some behaviors are dangerous to the individual or those around him or her. Suicidal or self-injurious behaviors or threatening assaultive behaviors are obvious examples of this category. One could also include behaviors that put the individual or those around him or her at risk due to faulty judgment, poor impulse control, or disinhibition. The second category of indicators includes behaviors, including treatment resistance, that tend to impede the treatment delivery process and successful rehabilitation. For example, an individual with TBI may start refusing therapy sessions or interventions. Another example might be attention deficits that are so profound as to preclude a person's participation in individual or group activities. The third category of indicators includes challenging behaviors that interfere with an individual's quality of life or threaten the integrity of their residential, social, or vocational settings. For example, loud repetitive outbursts, or preservative behavior may not be dangerous to the individual or those around them and may even be tolerable in the current residential, social, or vocational setting. However, improved medical or self-management of these behaviors might open new vistas in terms of progress toward a less restrictive residential setting, greater community integration, or more a competitive job placement. At the point that challenging behaviors fall into one or more of these categories it is reasonable to consider neuropsychiatric intervention.

Getting the most out of a neuropsychiatric assessment. It is important to consider the goals of neuropsychiatric treatment in the above context and to clarify this from the start. Usually, the neuropsychiatric goal is not to eliminate all challenging, target behaviors but rather to reduce the frequency or intensity of them enough that they no longer meet the threshold for being dangerous to self or others, interfering with the rehabilitation process, or preventing achievement of a better quality of life. In order to achieve this goal, it is critical to have a consensus between the individual, his or her family/caregiver system, and the physician on (1) exactly what are the challenging behaviors, (2) in what context do they occur, (3) how often do they occur, and (4) what is the intensity of the behaviors. Failure to agree on these four elements and failure to agree on a common language for describing and quantifying them usually results in an unsuccessful consultation.

Neuropsychiatric input is often needed. In addition to the changes in personality already described above, TBI is associated with dramatic increases in frequency of psychiatric illness. Estimates vary but the relative risk for developing problems such as depression, mania, psychosis, anxiety disorders and other problems increases two to seven fold compared to those without TBI. Complicating the situation further, these disorders often present in unusual or atypical ways that can be hard to recognize or diagnose. This is in large measure because the symptoms must be expressed through the residual motor, sensory, speech/language, and cognitive abilities that are deficient as a result of the brain injury. For example, how does someone with a severe speech/language deficit express that they are depressed? Or, how does manic hyperactivity present in an individual with impaired mobility (e.g., someone with quadriplegia)? So, it is helpful to consult with

someone who is familiar with the increased risk of psychiatric illness in individuals with TBI, and how the presentation of these disorders can be altered by other sequelae of the injury.

Be aware that it is not always possible to make an accurate assessment of the cause of challenging behaviors during a first visit. These behaviors are usually a complex mixture of pre-injury tendencies, traits, or behaviors; the profile of the brain injury (e.g., what part of the frontal lobe is injured); and the environmental and psychosocial context in which the behaviors occur. Often a neurobiopsychosocial assessment is conducted over a series of visits to address these multiple domains.

Quite commonly, treatment will involve developing a “differential diagnosis” which is a list of possible factors or diagnoses that are driving the challenging behaviors, and then outlining a list of interventions that might reduce the frequency and intensity of the target behaviors. Sometimes, these treatment interventions are actually part of the diagnostic process. Making a diagnosis of depression as a cause of the irritable behavior and prescribing antidepressants as a treatment is an example of this scenario. A dramatic reduction in the frequency and intensity of the target behavior (irritability in this example) might be taken as presumptive evidence that the diagnosis was correct. Failure to respond is less helpful because it might signify that either the diagnosis was incorrect or that the individual simply did not respond to the chosen antidepressant. Such failure results in a re-thinking of the diagnosis and perhaps an alteration in the treatment plan. The individual may come to feel as if they are the subject of an experiment but it is sometimes the most rationale way to proceed and is far better than having no diagnostic formulation. With this process, it is okay to be wrong, but it is not okay to be a sloppy thinker.

Neuropsychiatric interventions. The interventions prescribed by a neuropsychiatrist may include recommendations for more neurodiagnostic tests (e.g., updated brain imaging or an EEG). If psychosocial factors are judged to be driving the target behaviors, there may be suggestions about how to alter the person’s routine or environment in such a way as to reduce the challenging behaviors. Depending on the cognitive capacities and awareness of an individual, recommendations may include counseling, psychotherapy, or behavior therapy. Quite commonly, suggestions are made for medications to reduce the frequency and intensity of the behaviors. Regardless of its specificity, each intervention must be targeted and tied to a specific diagnostic formulation. The diagnostic formulation must drive the treatment plan.

Use of Neuro-Pharmacological Medications

By Randall Evans, Ph.D.

Brain injury can result in a wide range of neurobehavioral syndromes that have a dramatic effect on an individual's recovery and eventual return to community living. The cause of these syndromes reflects a complex interplay between the type and extent of the injury and the environmental variables at work post-injury (e.g., rehabilitation, family dynamics, or an individual's emotional status). This section will focus on the use of medications that are currently available to treat the more serious neurobehavioral complications post-injury and the underlying rationale as to why these medications may or may not be effective in persons with TBI.

Although it is well known that many parts of the brain are vulnerable to damage (which may be reversible in some cases, permanent in others), there are certain brain regions that are more exposed in a traumatic injury and are therefore more likely to be associated with neurobehavioral consequences. If we have a clear understanding of the nature of the injury (e.g., mild to severe or location of primary and secondary injury to the brain), as well as the pre-injury make up of the injured person (e.g., their pre-injury ability to tolerate stress and overall health status), then it is possible to recommend a rational approach to medication management.

Some common neurobehavioral consequences. This document will focus on behaviors that tend to “disqualify” the injured person from achieving the best possible outcome and those that often warrant aggressive neuro-pharmacological intervention.

For example, common, post-injury neurobehavioral problems are:

- aggression,
- irritability/anger,
- lack of motivation/apathy, and
- learning/memory and attention disorders.

While none of the above problems have an absolute location of function within the brain, research indicates that when these problems complicate everyday living, we need to get to some understanding of the underlying neurological components before suggesting a neuro-pharmacological approach. In fact, studies of brain “mapping” and of neuro-transmitter dysfunction post brain injury offer important insights on how medications can reduce or even eliminate the pathological consequences of these problems.

The most commonly prescribed medications for control of neurobehavioral problems after TBI are:

- anti-depressants,
- anti-convulsants,
- psycho-stimulants,
- anti-anxiety agents, and
- major tranquilizers (i.e., anti-psychotics).

Each class of medications has certain affinities for being absorbed in various parts of the brain and in various neuro-transmitter systems. With a clear understanding of the likely origins of the behavioral problem (i.e., which area of brain injury is likely to be causing the problem and which neurotransmitter system(s) have been negatively affected), the physician can begin a course of reasonable psycho-pharmacology. However, there are no medications specifically for use on persons with brain injury that are currently approved by the Food and Drug Administration. So, when medications are prescribed for managing neurobehavioral problems post-injury, they are done so under “off label” usage. “Off label” usage is perfectly legal and common but it does remind us that we are using medications that have been borrowed, from other diagnostic groupings (i.e., persons with non-traumatic depression, Parkinson’s Disease, non-traumatic seizure disorders, Alzheimer’s Disease, etc.).

There are principally **four neurobehavioral syndromes** that can occur following TBI that can significantly impede optimal recovery. They are:

- *Orbital Frontal Syndrome (OFS)* often results in problems with disinhibition, attention span, impulsivity, poor problem solving, and preservative/repetitive behavior.
- *Medial Frontal Syndrome (MFS)* often results in problems with diminished initiation, lack of spontaneity and follow through, and lack of insight.
- *Dorsal Lateral Syndrome (DLS)* often results in apathetic behavior, personality changes, and catastrophic emotional behavior (e.g., emotional over-reaction to minor events).
- *Temporal Lobe Syndrome (TLS)* can result in quick unpredictable behavior, excessive mood swings, and severe memory problems leading to confusion and anger.

These syndromes often coexist due to the common diffuse nature of brain injury. So, yes, there can be a rational approach developed to pharmacologically manage them due to distinct neuro-transmitter usage within distinct brain regions. For example, the OFS may, in part, occur because of disruption of the dopaminergic and epinephrine/norepinephrine neurotransmitters. Medications which may correct this disruption include most psychostimulants (e.g., Ritalin, Dexedrine, Metadate, Provigil, and Adderall) and most anti-Parkinsonian agents (e.g., Sinemet, Parlodel, Permax, Symmetrel, and Eldepryl). While none of these medications should be seen as a cure, responsible administration of these and similar acting medicines can lead to improvement of OFS and associated problems.

With MFS, a disruption of the dopaminergic neuro-transmitter system can also be accompanied by a disruption of serotonergic neuro-transmitters. Medications, including those listed for improving OFS problems, may also include “activating” tricyclic anti-depressants (e.g., Remeron, Parnate, Nardil, Tofranil, Pamelor, Aventyl), as well as new anti-depressants (e.g., Effexor and Lexapro).

With DLS, a relatively new class of medications called selective serotonergic reuptake inhibitors (SSRIs) show considerable promise. These include familiar medicines like

Prozac, Paxil, and Zoloft. Anti-seizure medicines, such as Tegretol, Neurontin and Depakote, may also help improve DLS problems.

With TLS and its complex and rich anatomical connections to the limbic system, several neurotransmitter systems can be affected by brain injury. These include serotonin, acetylcholine, and gamma-amino butyric acid (GABA). The prescribing physician has to sort out which medicine, or combination of medicines, will be most helpful with TLS-related behaviors. In addition to those listed above in the serotonin class, Neurontin, Exelon, and Aricept are potential medicines for TLS.

As you can see, it is important that the prescribing physician not only take into account the problematic behaviors that persons with brain injury are exhibiting but also the potential neuro-anatomical basis of those behaviors. While it is highly unlikely that any specific medicine will result in 100 percent treatment effectiveness, having an appreciation for the physiological basis of behavior problems can lead to an increased likelihood that an individual will respond positively to a particular medicine (based upon the medicine's neuro-chemical properties as they relate to the injured part(s) of the brain).

Neuropsychology

By John Capuco, PsyD

A neuropsychological evaluation is a comprehensive assessment of an individual's cognitive, emotional, and behavioral functioning utilizing both standardized tests and behavioral observations. The evaluation provides information regarding an individual's overall function and gives a profile of individual strengths and weaknesses that can be correlated with particular areas of the brain. This type of assessment can help in the planning of various activities, such as rehabilitation.

Typically, a neuropsychological evaluation will include assessments for:

- working memory and attention;
- processing speed;
- ability to understand and express language;
- visual processes;
- motor functioning;
- memory and learning;
- executive functions including reasoning, problem solving, planning, synthesizing, and organizing; and
- emotional functioning.

Using an individual's performance on individual tests, an evaluator is able to identify their core deficits and their impact on functioning in other cognitive and behavioral domains. In this way, the evaluation can aid in identifying limitations in activities of daily living and designing rehabilitation strategies.

Referring for neuropsychological assessment

While not everyone who exhibits cognitive or behavioral difficulties after a TBI needs to be referred for a neuropsychological evaluation, there are a number of reasons that an individual may be referred:

1. **To confirm or clarify a diagnosis and establish an individual's prognosis and rehabilitation potential.** Neuropsychological evaluations often aid in the diagnosis of various neurological disorders and serve as an adjunct to a diagnostic workup. Historically, neuropsychological evaluations were utilized for the detection and location of brain damage. While this function has been largely replaced by MRI and CT scans, neuropsychological evaluations continue to be more sensitive to the functional manifestations of brain impairment than either an MRI or a CT scan. They are often used in the diagnosis of mild TBI or brain injury due to metabolic or toxic disorders (where MRI and CT scans are often not revealing). Neuropsychological evaluations can also help differentiate between psychiatric and neurological disorders and help us better understand the role of psychiatric and personality issues in an individual following a TBI.

2. **To help in development of a care plan.** Assessing an individual's cognitive strengths, limitations and learning styles, as well as their behavioral, emotional and personality functioning, facilitates the planning and development of an effective care plan. The care plan includes the development of a rehabilitation or training program. With full understanding of an individual's neuropsychological status, realistic goals can be set, increasing and promoting an individual's chance for success in the community. A profile of an individual's strengths and limitations can be used to guide rehabilitation, educational, and vocational services. It is often used to address issues such as an individual's ability to manage legal and financial issues, participate in medical and legal decisions, live independently, drive, and return to work or school. Additionally, a neuropsychological evaluation can provide specific recommendations regarding the level of care required and can help determine if supervision and supports will be needed, including what kind and how much. Finally, it can help determine when changes in level of care should be made.

A neuropsychological assessment not only aids in the understanding of an individual's cognitive status, but also his or her personality traits and current adjustment issues. It is not uncommon that a plan of care is ineffective because of a failure to take into account these personality and adjustment issues. This can lead to presentation of a plan that clashes directly with these issues, such as the individual's need to be independent or their inability to see themselves as having cognitive difficulties. In these instances, having an accurate understanding of personality and adjustment issues will go a long way toward alleviating these kinds of difficulties.

3. **To help in development of rehabilitation strategies.** With a profile of strengths and limitations developed through a neuropsychological evaluation, appropriate recommendations can be made for utilization of various rehabilitation techniques and learning styles to enhance the individual's success in rehabilitation. This can help increase their level of functioning. Appropriate referrals can be made to specialists such as cognitive rehabilitation therapists, neurologists, psychologists, psychiatrists, nurses, special education teachers, behavior analysts, and vocational counselors.

With the knowledge provided by a neuropsychological evaluation, a physician or treatment team is in a better position to develop appropriate strategies that aid an individual in compensating for his or her limitations by relying on strengths and various cognitive or other assistive devices. There can be greater success matching an individual's abilities with his environment/workplace and utilizing a person's strengths to maximize their level of independence.

4. **To establish a baseline level of functioning and effectiveness of treatment technique.** A neuropsychological evaluation is often requested to establish an individual's baseline level of functioning. This baseline allows for ongoing monitoring to determine any decline over time or, in instances of treatment, to determine the effectiveness of the treatment. With ongoing assessment, the neuropsychologist and clinical team are better able to make appropriate and timely

adjustments to the rehabilitation plan and strategies, increasing likelihood of success for the individual.

Referring for functional neuropsychological assessment

Questions to be answered by a neuropsychologist vary with individuals and are dependent upon a number of factors including where the individual is in the rehabilitation process. What are his strengths and limitations? What are his goals? Effective communication is all-important between the neuropsychologist, the referring/treating physician, the therapists, and the individual with brain injury and family. It is the responsibility of the neuropsychologist to communicate with all these persons and obtain necessary information on referral questions and issues surrounding rehabilitation goals.

In general, early assessment and intervention improves outcomes following TBI. With early assessment, individuals and families can gain much needed information and avoid the development of secondary symptoms such as depression and anxiety. This is especially true of individuals with mild or moderate TBI where an individual's appearance and physical functioning are at odds with his or her cognitive and emotional functioning. Early assessment and intervention often helps reassure individuals of their reality, gives them simple compensatory strategies, and alleviates much anxiety and depression.

The nature of the evaluation will change depending where the individual is in the rehabilitation process and specific goals for the evaluation. While a comprehensive evaluation is not typically warranted during the early stages of recovery, a referral for a neuropsychological consult is still recommended. In these instances, a neuropsychologist can be of benefit in monitoring an individual's recovery and guiding rehabilitation efforts with several brief assessments. In general, neuropsychological tests were developed as indicators of brain functioning and not to predict real life abilities. Care must be taken in utilizing neuropsychological evaluations to predict how an individual will perform and function within a given context or environment. For example, it is common for an individual to perform poorly on neuropsychological testing and the predication be made that he or she will have difficulty driving. Due to the over learned nature of the task of driving, however, the individual will perform much better then the test prediction when placed behind the wheel of a car. For this reason it is often useful for a neuropsychological evaluation to be supplemented by a functional evaluation.

Behavior Analysis

By Marty McMorrow, MS

It is not surprising that the language and design of behavioral interventions in brain injury rehabilitation often mirrors that used more typically by behavioral psychologists, analysts, and specialists in other areas of disability. Even so, it is important to consider that current behavioral assessment and intervention practices are likely to continue to evolve in ways that are increasingly sensitive to the specific disabilities they are intended to address. Models more specific to brain injury do exist. Here we offer a broad overview of behavioral intervention.

Behavioral assessment. In the simplest terms, behavioral assessment is intended to identify factors that influence human behavior and provide the basis for interventions designed to change that behavior. Behavioral diagnostics, functional assessment, and functional analysis are general terms that have been used recently to describe these assessment techniques. Although each technique differs with respect to the source or basis of information gathered during the assessment (e.g., interview, retrospective analysis, questionnaire, analogue data, ongoing episodic data, etc.), they do share a few common goals. First, such assessments are designed to isolate and define behaviors of interest (e.g., needed skills and unwanted behaviors). Second, they are designed to identify the reasons or causes of existing behavior. Finally, they are designed to provide the background or rationale underlying any recommendation related to intervention.

Person-centered planning. In many contemporary service settings, the results of the behavioral assessment are likely to be used as part of a person-centered planning process. This process is generally intended to incorporate the findings of the behavioral assessment with other information gathered by the team in order to align the behavioral support plan with the broader individual support or rehabilitation plan. More than anything else, person-centered planning is intended to help insure that the plan is consistent with the individual's life history and future interests. Person-centered planning is especially relevant to individuals who have experienced a brain injury.

Person-centered planning is not a single set of practices that can be applied in any individual situation. At best, it is a mindset that drives a team or agency's commitment to putting the individual with TBI in the driver's seat of his or her life, rather than having others impose their judgments. According to Everson and Reid, "person-centered planning describes a number of value-based approaches for thinking about, communicating with, assessing, planning for, and supporting people with disabilities."⁶ Although there are several different ways to incorporate person-centered planning into a rehabilitation or treatment environment, some common elements of the process include:

⁶ Everson, JM and Reid, DH. *Person-Centered Planning and Outcome Management*. Habilitative Management Consultants, Morganton, NC. (1999).

- establishing a support team as inclusive as possible (e.g., the individual with a brain injury, family, preferred others, providers, etc.);
- creating a personal profile based on a broad array of assessment and other information;
- defining key roles of the individual and others on the team;
- creating a document that clearly communicates the future interests, preferences, and dreams of the individual;
- clarifying specific actions and goals set by each member of the team; and
- identifying ways to monitor and evaluate results.

Behavioral support plans. Similar to the way the behavioral assessment contributes to the person-centered planning process, a behavioral support plan may emerge as one of the results. Certainly not everyone who experiences emotional, cognitive, or behavioral residuals from brain injury will need a formal behavior support plan. Clearly, informal or interactive approaches to intervention are preferred when they are effective. However, when behavioral issues constitute a significant concern, prevent full participation in other aspects of one's life, or entail risks for the individual or others, then a more formal approach to behavioral intervention may be needed.

Organized approaches to behavioral intervention are labeled in many different ways, such as individual behavior plans, behavior intervention plans, personal intervention plans, positive behavioral support plans, or behavior support plans. Regardless of what they are called, they are likely to include common elements. They should be related to some form of behavioral assessment. To the extent possible, they should also involve the individual and other team members in their design and implementation. Finally, it might now be expected that they would focus as much or more on compensatory skill development through positive reinforcement approaches as opposed to more traditional behavioral methods intended to simply reduce unwanted behavior or control risks.

Regardless of its label, a behavior support plan is likely to include sections addressing the following areas:

1. Events that may precede behavior(s) of interest. If providers are to become more proactive in their approach to behavioral intervention, consideration of events that precede the occurrence of unwanted behavior is necessary. In most cases, these events will be characterized with words such as *predispositions* (i.e., conditions or states that increase the likelihood of experiencing difficulty like being tired, a recent seizure, or a particular medication) and *antecedents* or triggers (i.e., external events that appear to be related to the onset of a behavioral problem). We need to know what events are likely to produce difficulties for an individual so that we can provide needed assistance before the display of unwanted behavior. This proactive approach makes particular sense for persons with brain injury, whose problem-solving skills may have been compromised.
2. Unwanted or problem behaviors. Although some behavior plans may still focus on a particular unwanted target behavior, it is becoming increasingly common to design plans so that they also identify behaviors likely to precede the more serious behaviors.

Unwanted behaviors such as physical aggression are typically preceded by other behaviors that could be useful as signals to the individual or others that a problem exists and intervention is needed. Some plans actually attempt to identify a sequence of behaviors (e.g., from least to most intense) that an individual may exhibit when he or she confronts events likely to produce difficulties. Using this information, a person providing assistance may either recognize the event or a behavior as an indication that behavioral support is needed.

3. Desired replacement behaviors. It has been recognized for some time that intervening in a way that reduces an unwanted behavior does not necessarily promote the emergence of more desired behavior an individual can use in future difficulties. Most contemporary plans identify desired replacement behaviors. In many ways, this is a key part of person-centered planning because the desired behaviors that are selected to increase typically come from demonstrated behavior at some point in the past (i.e., they are within the individual's skill set). Focusing on what an individual can do instead of the unwanted behavior he or she demonstrated in the past is an important piece of the behavior plan, setting the stage for more proactive or supportive intervention.
4. Interpersonal Supports. These are specific actions or interventions that persons providing support can use when they notice either the events or behaviors that precede a significant unwanted behavior. In most cases, these supports will take the form of individualized requests, instructions, prompts, and encouragement to use the replacement behaviors that have been identified, accompanied by heavy doses of positive reinforcement. In more complex situations, the plan may need to be much more detailed. The interpersonal supports section of any plan should include actions that persons providing support will utilize in the event that more proactive intervention is not effective and more intense unwanted behavior occurs. Desired actions from those who provide support may also be arranged in a hierarchy from least to most support, including recommended de-escalation techniques, risk management protocols, and emergency interventions.

In conclusion, here are a few other suggestions about behavioral intervention:

- 1. Include the individual in creation of his or her own plan.**
It is difficult to overemphasize how valuable this can be. Approaching the plan as something that belongs to the individual (e.g., as opposed to the therapist or team) can have a huge impact on the individual's receptiveness to assistance at times when intervention is needed.
- 2. Shorter and simpler is better.**
The most useful or applicable plans are likely to be created with language and terms that everyone can fully understand.
- 3. It is a continuing process.**

It involves ongoing collection and dissemination of information related to the program's success and ongoing adjustments during implementation. A good behavioral intervention plan can be viewed as a compensatory strategy for emotional and behavioral self-management continuing for life.

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Part V: Some State Approaches

In many ways, the emergence of specific services and supports for persons with brain injury has paralleled the development of emergency and medical technologies designed to save lives. Human service professionals, State Agencies, families, and advocacy groups have had a much longer history of involvement in other areas of disabilities (e.g., mental health and developmental disabilities). Considering that much more time has been given to development of public support systems designed primarily for other disability groups, it is not surprising that development of brain injury services and supports often mirrors and frequently interacts with those systems.

Perhaps nowhere is the influence and interaction between disability service systems more evident than in the area of neurobehavioral health. For a host of reasons, persons who exhibit the most intense social, emotional, and behavioral issues following brain injury are frequently treated within systems of care not designed for them. For example, persons with brain injury who were injured prior to age 21 are frequently supported by State mental retardation/developmental disabilities (MR/DD) waivers as an “other related condition.” While the availability of such services sometimes may be viewed favorably, it is well known that many State-supported MR/DD waiver providers struggle with this area of care and many persons with TBI would not choose to be treated in this way if other, more specific, service options were available.

Similarly, persons with TBI who exhibit potentially dangerous behaviors frequently find themselves involved in mental health or psychiatric service systems that may or may not be equipped to address issues many would view as being unique to brain injury. In fact, it has been difficult to determine the number of individuals involved in mental health systems who are actually experiencing the neurobehavioral effects of TBI (due to the frequent interaction between psychiatric misdiagnosis and TBI).

Finally, there is increasing concern about the number of persons with TBI (and other disabilities) who are currently in prison or correctional systems. Many are there because there is simply no other place for them to receive appropriate service or supports. In a recent survey, program representatives and experts were asked to describe individuals with TBI who have the greatest difficulty in accessing services, and to identify the consequences of this difficulty. The respondents identified three groups who have the most difficulty accessing services as 1) individuals with cognitive impairments but no physical impairments, 2) individuals without personal advocates, and 3) individuals who exhibit problematic behaviors. This survey reported that most of these individuals ultimately end up homeless or in nursing homes, institutions for persons with mental illness, prisons, or other institutions.

There are several specialized neurobehavioral providers who, in some cases, serve and support persons with intense needs from several different States. And while progress may be occurring in some locations throughout the country, it is also clear that much more progress is needed. To help facilitate that progress, the National Association of State Head Injury Administrators’ *Guide to State Government Brain Injury Policies*,

Funding, and Services (2nd Edition, 2005)⁷ provides profiles of activities at the State level related to funding and services for persons with brain injury.

In the following sections, we review the activities and systems development and improvement initiatives of several States in greater detail. Based on these States' shared successes and lessons learned, we offer these recommendations to further systems development. (These recommendations are also listed in Appendix A.)

Identification

Increased identification and awareness of neurobehavioral residuals is needed to drive service development tailored to these unique and intense needs.

Collaboration

Considering the scope of the problem (e.g., 80-90,000 will experience the onset of long-term disability as a result of TBI annually⁸), collaboration between all constituents is a requirement...not just a nice idea.

With the tightening of insurance coverage and limited access to public support, every single support dollar available is needed to scratch the surface of the TBI problem.

Professionals need to be responsive, work as a team, and advocate to identify cohesive approaches at both individual and systems levels.

Collaborative systems of service and support must be strengthened by real technological innovations that contribute to functional outcome in the lives of persons with TBI.

If brain injury services and supports are going to be integrated within existing systems (e.g., MR/DD, MH, Corrections, etc.), then applicable, detailed, and creative protocols are needed to orient and promote relevant practices within these systems.

Public/Legislative Awareness

The dollars available do not match the magnitude of the need. Therefore, a new, innovative, and pervasive plan is needed to promote public/legislative awareness of the long-term consequences of brain injury.

⁷ Order a copy online at: <http://www.nashia.org>.

⁸ Langlois JA, Rutland-Brown W, Thomas KE. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta (GA): Centers for Disease Control and Prevention, NCIPC; 2006.

The Alaska Experience

Circumstances leading to development of a TBI program

In 1998 Alaska's Division of Public Health received funding from the U.S. Centers for Disease Control and Prevention to initiate traumatic brain injury (TBI) surveillance. Soon, it began to systematically quantify what had previously been perceived as a significant and growing public health problem. Around this same time, an Alaskan chartered State affiliate of the Brain Injury Association of America (BIAA) was established and became known statewide. Individuals with TBI and family members progressively organized and provided testimony to a variety of statewide planning bodies, administrators, legislators, congressional delegations, and anyone who would listen.

The Alaska Mental Health Board (AMHB), one of Alaska's planning bodies, acknowledged some responsibility for people with Organic Brain Syndrome (OBS) (which includes TBI) in their planning document, *A Shared Vision II: A Strategic Plan for Mental Health Services in Alaska 1999-2003*. The AMHB called for 1) a cogent plan for the population, 2) a responsible State Agency clearly defined and funded to serve people with OBS, 3) a multi-agency steering group to address pooled funding, community-based, person-centered services, and wide application of screening tools to enhance identification, 4) specialized training based in science and best practices, and 5) a guide for funding and services.

Working together the Brain Injury Association of Alaska, the AMHB, the Governor's Council on Disabilities and Special Education, and the Division of Mental Health and Developmental Disabilities secured funding from the Alaska Mental Health Trust Authority to pilot community-based, neurocognitive rehabilitation and to strengthen a State of Alaska application for Federal funding for TBI from the Health Resources and Services Administration (HRSA).

All of these events led to the State of Alaska, Department of Health and Social Services, Division of Mental Health and Developmental Disabilities (now known as Division of Behavioral Health), successful application for HRSA planning and implementation grants under project leadership of Leonard Abel, Ph.D., Community Mental Health Services Administrator. The Division of Behavioral Health has become Alaska's lead State Agency for TBI.

Through the process of conducting a statewide needs and resources assessment, Alaska learned that a significant percentage of individuals with TBI were/are not reaching their vocational, housing, and social goals due to disabling neurobehavioral sequelae. Alaska, therefore, began its TBI systems work on neurobehavioral issues.

Strategies for enlisting support of top government staff/legislators

Alaska's TBI advocates were quite adept at learning who within Alaska State government (including planning bodies) was willing to listen and help, knew State government well enough, and had the ability/power to help the movement along and bring about change, however incremental.

Key players

The key players in Alaska's early conceptualization and development were individuals with TBI and family members; Brain Injury Association of America-Alaska Chapter; Alaska Mental Health Board; Governor's Council on Special Education and Disabilities; Alaska Mental Health Trust Authority; and the Alaska Department of Health and Social Services, Divisions of Public Health, Senior and Disabilities Services, and Behavioral Health. More recently the key players have included the Governor's Advisory Board on Alcoholism and Drug Abuse; Alaska Commission on Aging; Disability Law Center (the TBI Protection and Advocacy grantee); and last, but not least, the Alaska Traumatic Brain Injury Advisory Board.

Program design

Alaska's beginning effort to systematically develop and deliver community-based service has taken a path of least resistance, consistent with findings from the statewide needs and resources assessment, as well as opportunity of the time. Neurobehavioral sequelae (e.g., cognitive, behavioral, and or emotional impairments) are significant barriers for many individuals with TBI. For example, some individuals with TBI have great difficulty in realizing personal goals for meaningful employment, social relationships, and safe, affordable housing.

In order to understand Alaska's approach, it is important to understand the Federal and State context in which its community-based services are being developed. Individuals with traumatic brain injury are served through various delivery systems including the existing Medicaid waiver programs administered through the Division of Senior and Disabilities Services, the Division of Vocational Rehabilitation, and the Behavioral Health agencies. While there is great interest in developing a TBI-specific Medicaid waiver, there is a significant waiting list for waiver eligibility and service. Community mental health centers are expected to serve prioritized populations utilizing grant dollars and Medicaid funding.

Alaska approached the task with several key considerations in mind, including fidelity to the needs of a significant number of individuals with TBI and family members, statewide system infrastructure, and a rationale and mechanism for financing service. Although this approach will not serve all individuals with TBI or their family members, it is a good beginning.

Let's begin with the rationale and mechanism for financing service. In recent years Alaska has joined the ranks of many States that are not able to fund existing services due to fiscal gaps. It has become very difficult to sustain existing services, let alone appropriate additional funds from the legislature for new services. In this context Alaska has defined prioritized service populations and endeavors to maximize Medicaid utilization whenever possible. Advocates anticipated that successfully prioritizing a newly identified population was going to be an uphill challenge at best. Among other populations, the Division of Behavioral Health has prioritized adults with serious mental illness and children and youth with serious emotional disturbance.

Although traumatic brain injury is an *injury*, its neurobehavioral sequelae, manifesting in the form of diagnosable condition(s) with disabling functional impairments, clearly fit the Federal definitions for serious mental illness and serious emotional disturbance, for adults and children and youth, respectively. Definitions for serious mental illness and serious emotional disturbance are:

Pursuant to section 1912(c) of the Public Health Service Act, adults with serious mental illness (SMI) are persons: (1) age 18 and over and (2) who currently have, or at any time during the past year had a diagnosable mental behavioral or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-IV or their ICD-9-CM equivalent (and subsequent revisions) with the exception of DSM-IV "V" codes, substance use disorders, and developmental disorders, which are excluded, unless they co-occur with another diagnosable serious mental illness. (3) That has resulted in functional impairment, which substantially interferes with or limits one or more major life activities.

Pursuant to section 1912(c) of the Public Health Service Act 'children with a serious emotional disturbance' are persons: (1) from birth up to age 18 and (2) who currently have, or at any time during the last year, had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-III-R.⁹

Historically and prior to Alaska's TBI efforts, the State adopted the much narrower definition of serious and persistent mental illness that limited the prioritized diagnosable conditions to disorders such as schizophrenia, bi-polar, schizoaffective, and the like, where psychosis was a persistent feature. As part of its State TBI Action Plan, Alaska has recently adopted the broader Federal definition. This adoption has paved the way to now include diagnoses such as personality change secondary to TBI, cognitive disorder not otherwise specified secondary to TBI, mood disorder secondary to TBI, and anxiety disorder secondary to TBI. All these must have resulting disabling functional impairments. These disorders are mentioned purely as examples and are not meant to be

⁹ Federal Register Volume 58 No. 96 published Thursday May 20, 1993 pages 29422 through 29425.

exhaustive of potentially applicable disorders referenced in the American Psychiatric Association's *Diagnostic & Statistical Manual IV-TR*.

By fully adopting the Federal government's July 2003 definitions for serious mental illness and serious emotional disturbance, the State of Alaska now allows individuals with TBI and disabling neurobehavioral sequelae to access State-funded community mental health center services. The ability to include these individuals among the prioritized populations provided access to and incorporation into an existing statewide infrastructure and mechanisms for both general fund and Medicaid dollars to support service delivery.

As mentioned before, Alaska's statewide needs and resources assessment revealed that the disabling aspects of neurobehavioral sequelae are often barriers to individual vocational, interpersonal, and housing goals. There has been much discussion about the community mental health system's ability and appropriateness to serve this population. Upon closer examination Alaska also learned that services such as case management and skills development can be very beneficial supports to individuals with disabling conditions. The Alaska Medicaid Plan for Community Mental Health Services provides this layer of service—known as both clinic and rehabilitation options. The plan includes case management and skill developmental services for as long as an individual needs (among other medically necessary services). So, Alaska's design is a hybrid, building upon the Federal government's effort to develop community supports for recovery and grounded in best practices.

The following services may not be available at all locations. They are differentiated for by clinic and rehabilitation services for purposed of Medicaid.

Clinic Services

- Initial Intake Assessment
- Semi-Annual Intake Assessment
- Psychiatric Assessment
- Psychological Testing and Evaluation
- Neuro-Psychological Testing and Evaluation
- Individual, Family, and/or Group Psychotherapy
- Pharmacologic Management
- Crisis Intervention

Rehabilitation Services

- Initial Functional Assessment
- Semi-Annual Functional Assessment
- Medication Administration
- Case Management
- Individual and/or Group Skill Development
- Family Skill Development (for ages under 21)
- Recipient Support
- Day Treatment

For more information on service descriptions and fees, see the Community Mental Health Center Billing Manual at <https://alaska.fhsc.com/documents/billing.asp>.

Successes

Establishing a means to include individuals with TBI and disabling neurobehavioral sequelae in prioritized populations served by community mental health centers is one of Alaska's first major successes in TBI systems development.

Alaska's Division of Behavioral Health is also embarking upon a system-wide initiative to integrate substance abuse and mental health services. This endeavor has led to cross-screening for the presence of co-morbid (i.e., mental health and substance abuse) conditions among all State-funded substance abuse providers and community mental health centers. Alaska has developed a screening tool to identify TBI among those with co-morbid conditions. Alaska now includes screening for suspected TBI as an integral component and as a statewide requirement.

The Division of Behavioral Health is in the midst of implementing a new Management Information System, the Alaska Automated Information Management Systems (AKAIMS). The system is designed to help the State move towards a data-driven integrated behavioral health system. The Alaska Screening Tool, including the TBI screening component, is built into the software. The AKAIMS will become an increasingly valuable tool in better understanding the numbers of individuals with TBI screened and served, as well as outcomes.

In Fiscal Year 2004 (when screening for TBI among all behavioral health grantees was voluntary) a total of 53 individuals were identified as having screened positive for a suspected TBI among participating community mental health centers. After screening became required in Fiscal Year 2005 and with data still coming in, our community mental health centers alone have reported screening 149 individuals with suspected TBI between July and September 2004. Screening is now required not only for all community mental health centers but also all State-funded substance abuse providers.

The importance of educational and training preparedness on the part of our community-based, behavioral health systems providers cannot be overemphasized in better serving individuals with TBI and disabling neurobehavioral sequelae. In 2003 (prior to required screening for TBI) a survey among behavioral health providers showed approximately 35 percent already served in excess of 200-plus individuals with TBI. A separate informal survey of community-based behavioral health providers reported a significant percentage reported being less than familiar with brain functioning, injury specific deficits, screening, assessment, differential diagnosis, treatment and rehabilitation, and recovery and referral. So Alaska elicited the expert consultation of Tom McAllister, M.D., and others to begin addressing our work force's needs in behavioral health education and training. Through these efforts Alaska has begun statewide and regional training.

Lessons learned/words of wisdom

Clearly, the State's adoption of existing Federal definitions for serious mental illness and serious emotional disturbance appears to be working well toward incorporating an existing statewide infrastructure for prioritizing eligibility.

Individuals with TBI have voiced strong reservations about accessing services from mental health centers. The message is "we have a TBI, not a mental illness." So, even though a statewide structure and extensive service array is available, some individuals with TBI are fearful of becoming stigmatized by accessing service from a mental health center.

Alaska has also learned, from an initial pilot site, that a significant number of individuals with TBI do not have Medicaid, typically as a result of not being considered disabled by the Social Security Administration. When the principal sustaining financing for services is largely Medicaid contingent, this is problematic.

The State's required screening appears to be very successful. While identification has increased, the providers' response of "Ok, we've identified them. Where do we refer them?" speaks to the ongoing need for professional development and training in TBI.

The approach Alaska has taken thus far is not designed to be all things to all States. Although Alaska's current effort focuses on disabling neurobehavioral sequelae in the cognitive, behavioral, and/or emotional sense, needs such as speech therapy, personal care attendants and the like—beyond the scope of behavioral health—exist. Alaska's philosophy is that behavioral health can and should minimally assist with linkage to those needed services, as part of its case management service.

Future program goals

Alaska needs to stay the course of enhancing the existing, community-based, behavioral health workforce to understand, identify, and service individuals with TBI and disabling neurobehavioral sequelae.

The Division of Behavioral Health will also engage its sister, Division of Senior and Disabilities, as well as other divisions and departments, to clarify respective complementary roles in Alaska's developing service system.

As the AKAIMS becomes fully functional, it will be incumbent to monitor utilization and service delivery to individuals with TBI from a continuous improvement perspective in order to articulate better and best practices.

Emergency psychiatric services are currently offered. Behavioral supports are contingent upon meeting prioritized population eligibility criteria and medical necessity. Funding grants are a combination of adult serious mentally ill and child and youth serious

emotional disturbance to community mental health center grantees and Medicaid, as applicable

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The Massachusetts Experience

Circumstances leading to development of a secure/locked neurobehavioral unit

The neurobehavioral unit (NBU) was designed and implemented by the Statewide Head Injury Program (SHIP) at the Massachusetts Rehabilitation Commission in response to the lack of an intensive behavioral treatment program in the State and the high need for this type treatment by the first SHIP eligible consumers (1985-1987). SHIP was required to serve people with TBI who were a risk to themselves or others—defined as a Priority 1 Group. Individuals with significant behaviors, psychiatric problems, and substance abuse issues were placed in out-of-State programs in States such as California, Texas, Virginia and Pennsylvania. The cost of these programs ran between \$200,000 and \$250,000 per year per individual. The State had no way to monitor these services due to the geographic distance. Also, families had no way of staying involved during the treatment period.

Key players

SHIP decided to develop a specialized neurobehavioral program for people with TBI that would combine cognitive, behavioral and pharmacological treatments in a locked program, with capacity for volunteer admissions or commitments. In reviewing licensure for locked facilities in the State, we learned that the Department of Mental Health needed to license this unit. The licensing category was carefully selected so as not to provide the court system with alternatives to jail. The unit was to be housed in a chronic care hospital, also requiring licensure from the Department of Public Health. Funded by SHIP with State dollars, it was designed with the ability to go third-party payer at the necessary time (including Medicaid). The State's Medicaid agency was also at the table. Establishment of a rate for such a specialized bed in this type of facility was determined by the Rate Setting Commission and based on a formula that included total revenue for the hospital.

The Rate Setting Commission was an active participant because the program was expected to result in an 18 to 24-month stay necessitating a waiver from the Utilization Review process. If this was to be a successful treatment program, it was critical to get a per diem rate that would cover the intensive additional costs (e.g., neuropsychologist, behavioral psychologist, behavior specialists, neuropsychiatry, higher patient ratio nursing, recreation therapy, social work and other necessary personnel). The entire interagency collaboration was led by the Executive Office of Health and Human Services. Individual families whose members had been sent out-of-State and the general advocacy community (via the Massachusetts Brain Injury Association affiliate) assisted in the effort by keeping the needs of this sub-population a priority within State government and human services.

Program design

The unit was designed as a 12-bed unit by SHIP's Chief Neuropsychologist, Fran LaVecchia, Ph.D. SHIP wrote a request for proposal and put it out to bid seeking a private provider, for-profit or not-for-profit, to implement and clinically manage the unit. The provider was required to partner with a facility in order to eventually access third-party reimbursement. A chronic rehabilitation hospital was chosen. It would be responsible for the physical plant, meals, laundry, etc. The treatment program was the domain of the clinical provider. The program targeted people with TBI who had rehabilitation potential or the ability to move back into the community after treatment. SHIP was the gatekeeper for all referrals and admissions. During the first two years, all of the costs of this program including room and board were absorbed through SHIP under a cost reimbursement contract. The start-up included extensive renovations for safety issues such as replacing windows with Plexiglas and covering old fashioned radiators.

Successes

It is thought that this unit was the first State-funded unit of its type in the country and served individuals dependent on public assistance for their needs. It was an excellent example of collaboration between private, public, and county systems. The original hospital setting was a county hospital.

This treatment approach has been enormously successful with the majority of participants carefully chosen by SHIP and the providers (based on histories and clinical profiles). SHIP worked closely with unit staff on discharge planning. Many participants transitioned to SHIP-funded programs that are twenty-four hours a day, seven days a week.

The providers immediately established an advisory group composed of key hospital staff, individuals with brain injuries and their family members, State Agency representatives, and community partners, including a Rabbi and a lawyer. A sub-committee of this group made up the Human Rights Committee. This level of involvement and activity helped to support the unit's operations over the past 15-plus years, at times when there was a question as to whether the unit could and should continue.

Lessons learned/words of wisdom

Unfortunately, a small subset of consumers exhibited chronic neurobehavioral problems which could not be ameliorated. They required a step-down, chronic program not fully community integrated (due to safety issues). Because one does not exist in Massachusetts, it created a "backdoor" problem for this program's turnover. The State of Massachusetts has discussed the need for such a unit, which crosses over many populations, but has never taken the next step to develop and implement one. It is critical

to budget and plan for community programs that people can transition into when ready. Lacking this resource individuals are highly likely to make significant gains and then decompensate while waiting for a discharge option to open up.

Because the unit was part of a hospital, the Director of Nursing at that facility had authority over a number of things that impacted the unit's day-to-day operations. The clinical director of the unit had to work very closely with this individual to educate her and negotiate specific issues. There was conflict between the traditional nursing model and the neurobehavioral treatment approach.

The first clinical provider awarded the contract had a background in psychiatric treatment. This was not the best clinical match for the needs of this population and resulted in a re-bidding of the contract, which was awarded to a vendor with brain injury experience.

In the third year, the unit shifted to third-party payers including Medicaid. SHIP was no longer the gatekeeper, resulting in admissions that may not have been totally appropriate. For example, the unit was designed for adults. Once funding shifted, young adolescent men who had special education ties were also admitted. The waiver for Utilization Review was no longer in place and this led to much shorter timeframes for treatment of this population. On a positive note, other State Agencies, serving people with brain injury and co-morbid diagnoses like mental retardation and mental health, tapped into the unit for services. The use by other systems made it a valuable State resource and worthy of continued attention and support at higher levels.

In order for the vendor to increase profit, the beds were increased to 16 which impacts treatment intensity and dilutes staffing patterns. On-the-clock-hours of the medical director, who was also the prescribing neuropsychiatrist, were reduced as well. Neuropsychology was eliminated as a treatment team position and the clinical director position was filled by a bachelor's level clinician. Qualified staffing is so important to the ongoing successful treatment of individuals with TBI.

Current behavioral supports

This unit was the first step in SHIP's development of a menu of neurobehavioral services. Massachusetts now has a secure/locked unit, community living programs twenty-four hours a day, seven days a week, and an in-home family assistance program to address behavioral issues that challenge the family after a TBI.

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The Minnesota Experience

Circumstances leading to the development of neurobehavioral hospital inpatient programs, and home and community-based services

The neurobehavioral services briefly described below relate to the development of both inpatient neurobehavioral hospital services as well as the development of home and community-based services. They target neurobehavioral supports through a Medicaid home and community-based TBI waiver. Of the inpatient units one is in the public sector, funded through a variety of third-party payers (not by State appropriations) and one is in the private sector.

Working with the Minnesota Medicaid State Plan personal care services and the Medicaid State Plan Rehabilitation Option/Crisis Services/Adult Rehabilitative Mental Health Services has contributed to expansion of behavioral supports in the community for certain eligible persons with brain injury. Minnesota has looked to Medicaid to provide significant supports for persons with disabilities.

The development of inpatient units and the development of the Medicaid waiver were virtually parallel and concurrent efforts in the early 1990s, primarily (though not alone) by the Minnesota Department of Human Services (DHS) TBI Program. As in other States, Minnesota Medicaid had been placing persons out-of-state for specialized neurobehavioral hospital services as none were available in the State. Persons with significant behavioral needs after brain injury were usually served in locked nursing facility units or mental health units. Even this was possible only if the family or an advocate researched the possibility and was willing to go through all the red tape, as well as difficulties brought on by distance, separation, and complexities of discharge/disposition planning. Sometimes out-of-state providers courted families and encouraged them to seek prior authorization.

Minnesota has managed to incrementally build and expand neurobehavioral services—in particular long-term, community-based services—and we have not placed anyone out-of-state on Medicaid for neurobehavioral services for several years. But, we have, by no means, addressed all of the complexities and neurobehavioral needs of persons with brain injury and their families. There are people that could be candidates for neurobehavioral services that are not aware of them or how to access them. Ombudsman, advocates, case managers, discharge planners, and corrections/legal system personnel need to be aware of this option. Though the TBI waiver can serve eligible persons of any age under 65, admission criteria indicate ages 18 and older at Bethesda Rehabilitation Hospital in St. Paul and 16 and older at the Minnesota Neurorehabilitation Hospital.

The strong demand for neurobehavioral services in Minnesota harkens back to brain injury-related needs and resources assessments and advocacy in the 1980s. The 1985 Minnesota Legislature mandated that the MN DHS establish a task force on the needs of persons with brain impairment to give recommendations to the Commissioner on funding and policy. Thanks to the advocacy of the Minnesota Head Injury Association (MHIA),

founded in 1984 by Elinor Hands (the first Executive Director) and others, head injury was one of the three categories of focus in the study (others were stroke and dementias). *The Needs of Persons with Brain Impairments Legislative Report* called for development of appropriate behavioral supports as well as many other services including case management, personal care, housing, and employment. In 1988, MHIA conducted the greater Minnesota needs assessment, calling again for a full range of accessible, appropriate services and supports—including behavioral supports specific to persons with brain injury—be made available statewide.¹⁰ The MHIA is now the Brain Injury Association of Minnesota.

Legislative support

Key to legislative success in Minnesota was MHIA's early and ongoing work with revered health care policy maker, Minnesota Senator Linda Berglin, who had a strong interest in disability services. Senator Berglin was instrumental in calling for the DHS Task Force and Legislative Report and in developing various subsequent policy and funding legislation for brain injury, including the Minnesota Statute, Services for Persons with Traumatic Brain Injuries, ch. 256B §093, 1989. It laid plans for the development of the DHS TBI Program. Also important was establishment of the TBI-dedicated funds for the TBI/Spinal Cord Injury Registry at the Minnesota Department of Health, operational since 1993.

As stated in the Minnesota Statute, Traumatic brain injury and spinal cord injury registry; purpose, ch.144 §662, 2005: "The purpose of the registry is to 1) collect information to facilitate the development of prevention, treatment, and rehabilitation programs, and 2) ensure the provision to persons with traumatic brain injury or spinal cord injury of information regarding appropriate public or private agencies that provide rehabilitative services so that injured persons may obtain needed services to alleviate injuries and avoid secondary problems, such as mental illness and chemical dependency."

Circumstances leading to development of inpatient, neurobehavioral hospital services

In the early 1990s the DHS TBI Program facilitated policy discussion on the DHS State Operated Services (SOS) Division (over the Regional Treatment Centers and State hospitals); the DHS TBI Advisory Committee; and the MHIA. Workgroups comprised of policy staff, advocates, and a Regional Treatment Center Task Force for the DHS TBI Advisory Committee took up the issue of identifying persons with brain injury in State regional treatment centers and pursuing development of appropriate clinical services and discharge planning, in addition to development of TBI waiver services.

¹⁰ *The Greater Minnesota Needs Assessment and Recommendations*, September, 1988, Minnesota Head Injury Association (now Brain Injury Association of Minnesota).

In 1993 an administrative policy and procedure was developed and implemented to screen all admits to State operated service (SOS) facilities for TBI. Training was provided statewide and ongoing technical assistance offered.

Meanwhile, Barry Johnson, M.D., a neurologist and mental health unit physician at Moose Lake Regional Treatment Center, recognized the need to address brain injury specifically and realized the potential to provide a better, specialized service. Because he had a number of patients with brain injury, he took the initiative to start a brain injury unit in 1992, without waiting for an official State blessing. Dr. Johnson and some of his clinical staff became involved in the SOS Admission TBI screening policy development. This TBI unit served as the “placeholder” for developing subsequent State-operated units when the Moose Lake Regional Treatment Center was ordered closed in 1993. Had Dr. Johnson not started a unit, there would not have been a specialized brain injury unit to save, rather just needs assessments, studies, and reports.

Through the advocacy of MHIA, legislation in 1993 ordered development of a 15-bed specialty unit for TBI at the Brainerd Regional Human Services campus. In 1995 Minnesota Neurorehabilitation Hospital (MNH) opened as a 12-bed, statewide neurobehavioral hospital licensed as a long-term care facility. It was diagnosis-related-group-exempt (DRG-exempt) by Medicare and able to bill Medicaid and other third-party payers because it was not an institute for mental disease. MNH is on a State campus, but it is a discreet entity now with 15 beds. Over the years, MNH has steadily expanded outpatient clinic and specialty/consultative services and is now known as Minnesota Neurorehabilitation Services.

The private sector counterpart, the Neurobehavioral Brain Injury (NBI) Unit, and related services at Bethesda Rehabilitation Hospital in St. Paul were developed largely through outreach by the DHS TBI Program to the hospital administration. The hospital was licensed as a long-term care facility, DRG-exempt by Medicare. Information shared included background on issue and needs, as well as examples of neurobehavioral programs and contacts around the country. Bethesda staff visited programs, researched the potential market, and worked with DHS TBI Program staff to assist in the development of a neurobehavioral hospital admission and continued stay criteria for medical necessity (Medicaid). The hospital opened its NBI Unit in 1993 and developed a Neurobehavioral Crisis and Assessment (NCA) Unit with shorter length of stay, to stabilize persons quickly and return them to their natural environment in 1995. The NBI and NCA units have a capacity of 29 beds total, with a unified staff that serves both. This allows seamless transfers and total integration across programs, units, and services. Bethesda Brain Injury Services offers a full range of inpatient rehabilitation. There has been steady expansion of neurobehavioral outpatient outreach and consultative services to professionals and community-based providers.

Both inpatient neurobehavioral hospitals offer very comprehensive and intense rehabilitative services in a secure environment. Their lengths of stay, though still measured in months on average, have decreased over time in direct relationship to policy expansion providing for brain injury behavioral service development and community

providers ramping up access to home and community-based services in local counties. It was recognized that persons would rapidly lose stability without access to sufficient, capable, community-based providers—with durability of outcomes certainly a critical factor in treatment. Discharge into a questionable setting, with insufficient services, is not a cost-effective investment for payers, as it is likely to fail. From a personal perspective, another loss or another failure for the individual with brain injury and his or her family to contend with is unconscionable. Significant supports by capable providers, plus contingency planning, need to be in place for successful discharge (i.e., one that provides an individual and those persons important to them with a good opportunity to have a real life). It can be done.

Circumstances leading to the development of home and community-based services—in particular, the TBI Medicaid waiver

DHS TBI Program (1990–1997) was funded by a 1989 statute largely as Medicaid Administrative Case Management, and later augmented by a portion of Minnesota’s TBI Dedicated Funds. The unit varied over time from seven to 11 staff, responsible for developing appropriate policy and services. Their work depended largely on effective collaboration and consultation with various internal Medicaid programs and State-funded, State-operated services. Policy and lead staff worked with central office peers to build awareness of brain injury, develop new policy and services, and look at ways to increase the appropriateness of disability services, such as personal care, by making them more responsive to the functional needs and nuances of brain injury sequelae. It was also important to work toward identification of persons with brain injury in various services and settings, including the Regional Treatment Center Admission screening. DHS TBI Program regional staff worked in each of Minnesota’s 87 counties, providing technical assistance, consultation, training, and outreach to counties, providers, stakeholders groups, etc. The DHS TBI Program was supervised first by Allan Weinand and later by Sharyl Helgeson.

Minnesota DHS already administered four home and community-based Medicaid waivers when the DHS TBI Program was established in 1990. The Program was extremely fortunate to have been located in the division that managed all but one of the waivers. Expertise and leadership support were plentiful to address the complexities of such related policy issues. In working with needs assessments, developing an advisory committee, and seeking input from other stakeholders, it was not difficult to ascertain that persons with significant behavioral needs due to brain injury were placed in the most restrictive settings (e.g., locked mental health units, jails, locked nursing facility units, etc). These settings/services were considerably expensive with questionable results. Sorely lacking were the neurobehavioral services to address the significant to severe cognitive, behavioral, and emotional needs of persons with brain injury over the long-term.

The Program considered amending the established nursing facility level of care waiver for persons with disability but such a proposal was rejected. That waiver looked across

all populations, with all functioning levels, in all nursing homes statewide, as a comparison group for types of services and cost effectiveness purposes. But persons with significant cognitive needs and behavioral needs due to brain injury were generally best served by specialized nursing facilities that advertised programs for persons with brain injury. These facilities received additional funding to provide rehabilitative services for brain injury and other populations needing rehabilitation. The decision was made to develop a new waiver, a TBI waiver, comparing only to this population in those specialized nursing facilities for types of services and cost effectiveness. The basic menu of services in place for the established nursing facility disability waiver was used as a base, but then expanded significantly for TBI. For example, the staff added various levels of behavioral supports (paraprofessional and professional), multiple types of residential supports, independent living skills therapies (e.g., music, art, recreation), living skills maintenance, as well as skills development and multiple day service supports options. In 1992 the Federal Department of Health and Human Services Health Care Financing Administration (now known as the Centers for Medicare and Medicaid Services) approved the Minnesota TBI waiver. While it was the second TBI waiver (just after Kansas), it was the first to heavily emphasize behavioral supports for persons with significant cognitive and behavioral functional needs. The TBI waiver was largely written by Debra Wesley, DHS TBI Program Policy Consultant, with input from various policy staff and the DHS TBI Advisory Committee.

Key players

- Elinor Hands (the first Executive Director of MHIA/BIA of MN) and her successor, Tom Gode, and their staff, have been essential in their work with legislators, key public agencies, providers, foundations, and for keeping persons with brain injury and their families informed and involved in public policy.
- DHS TBI Advisory Committee, launched in 1990 and in statute as Commissioner-appointed since 1991, has been instrumental in supporting brain injury policy and service recommendations. Over time, its working subcommittees have reorganized. In the past, a Regional Treatment Center Task Force provided focus. Now, it is organized more broadly, across department divisions (e.g., State-operated services, adult mental health, children's mental health, and chemical health) to better address behavioral health services for persons with TBI. This group also serves as the State TBI Advisory Council for purposes of the HRSA's Federal TBI Program State Agency TBI grants.
- Since 1993 Robert L. Karol, Ph.D., L.P., Director of Psychology/Neuropsychology and DHS TBI Advisory Committee member and Program Director of Brain Injury Services; Robert Sevenich, M.D., J.D., Medical Director of Brain Injury Services; and the administrative and clinical staff at Bethesda Rehabilitation Hospital, St. Paul.
- Since 1995 Donald Starzinski, M.D., Ph.D., Clinical Director, and Gregory Murrey, Ph.D., L.P., Director of Neurobehavioral Services (and DHS TBI Advisory

Committee member) and the administrative and clinical staff at Minnesota Neurorehabilitation Hospital (MNH), Brainerd, MN.

- Erwin Concepcion, Ph.D., L.P., Director of Behavioral Health Services, Anoka Regional Treatment Center (past DHS TBI Advisory Committee member), hired in 1992 as the first clinical neuropsychologist in State Operated Services, Regional Treatment Center System. In addition to his clinical services and management roles in the metropolitan area, he has presented several times on the crosswalk between mental health and brain injury services to help the translation for policy makers, professionals, providers, case managers, etc. The SOS system now has four staff clinical neuropsychologists, including Dr. Murrey at MNH.
- Because Minnesota operates as a State-supervised/county-administered system, screeners, case managers and others at the County Human Services and public health agencies in all 87 counties are truly where the “rubber meets the road” for individuals eligible for Medicaid. It is at the county level that persons on Medicaid can access waivers and personal care. Persons with brain injury accessing Adult Rehabilitative Mental Health Services (ARMHS) may or may not have a county mental health case manager. Assessments are completed by ARMHS providers.

Program design

The waiver has two levels of care: TBI-NF (specialized nursing facility) and TBI-NB (neurobehavioral hospital). The menu of services is not different between them, rather the amount of available resources/services varies based on intensity of need.

States have some discretion with home and community-based waiver development. In Minnesota a person does not have to be exiting a specialized nursing facility or neurobehavioral hospital facility to be eligible for that level of care (“conversion”). The person can require the type of services/level of care and be eligible as a “diversion.” Not all persons on the TBI-NB waiver have been inpatients in a neurobehavioral hospital. Many have been in an inpatient at a State Regional Treatment Center (State hospital) or other mental health setting.

See the Minnesota DHS Web site at www.dhs.state.mn.us to find specific details on eligibility, menu of services, provider standards, etc.

Circumstances leading to work with other Medicaid State plan, community-based services

Personal Care Assistant (PCA). Minnesota was one of the earliest States to develop the personal care program and offer it as a Medicaid State Plan service, not just as available through a Medicaid HCBS waiver. Through multiple policy task forces in the 1990s, the service definition was expanded and developed to include support for cognitive and

behavioral functional needs, not merely physical care. The personal care program offers the flexibility to be more medical, or more behavioral in nature, and to provide the appropriate medical or behavioral supervision to direct care staff in the development of appropriate care plans. In addition, the PCA program has developed options that emphasize consumer direction. Certain personal care providers have developed specialized services to address the needs of persons with brain injury, and some have specialized for persons with mental illness, etc. Persons with TBI are assessed by the local county public health nurse, and if a person has very significant needs, PCA supports can be significant (up to a Regional Treatment Center level of need).

Rehabilitation Option/Crisis Services/Adult Rehabilitative Mental Health Services. The legislation authorizing ARMHS refers to persons with mental illness or traumatic brain injury, though the person must have a primary diagnosis of mental illness to be eligible. A full range of basic living skills/social skills, community intervention, and medication education are available. For details on eligibility and covered services, see the link at the end of the section. Some providers specialize in serving persons with brain injury. Eligible persons must be at least 18 years of age with significant disability and functional needs that meet program requirements.

Successes

- MN has maintained and steadily gained neurobehavioral capacity by means of incremental policy and services development, linked expansion, and slowly building provider capacity and awareness of the specialized service options. We used the development of inpatient units and placement of persons in out-of-state neurobehavioral hospitals (in 1992) to expand the TBI waiver from just a Specialized Nursing Facility level of care to adding the Neurobehavioral Hospital level of care in 1994.
- Success as of August 2005:
TBI waiver – Nursing Facility serves 926 persons
TBI waiver – Neurobehavioral Hospital serves 314
- An Unintended Plus: The TBI waiver became quite the vehicle for building TBI awareness across the State, from facility discharge planners to county case managers to family members, etc. It raised interest from all directions causing providers and others to seek training, develop capacity, adapt, link with specialty providers and brain injury stakeholders, and respond to the need and the “new market.”

Select current behavioral supports offered through Minnesota Medicaid

1. TBI waiver
2. Personal Care Assistant (PCA)

3. Rehabilitation Option/Adult Rehabilitative Mental Health Services (ARMHS) for persons with eligible diagnosis of mental illness
4. Neurobehavioral rehabilitation hospital services
5. Neuropsychological assessment, rehabilitation, and case/team consultation services
6. Cognitive remediation training programs

Lessons learned/words of wisdom

Advocacy is what has worked best through the years. Advocates have included Brain Injury Association (BIA) chartered State affiliates, persons with brain injury/families, DHS TBI Advisory Committee, internal agency staff, interagency colleagues. Also, persistence, partnerships, targeted risks, strategies development, and anticipating the need to provide justification has helped advocacy efforts. At times, it has been two steps forward and one step back but making a difference, even incremental one, motivates.

Minnesota took on and is still working in both worlds to 1) develop specialized brain injury services, 2) make more generic disability/functional behavioral health supports more sensitive and responsive to brain injury nuances, and 3) do better to identify people with brain injury in various populations, all while building capacity.

Having a State TBI Registry is fundamental. It gives credibility, visibility, important partnerships and valuable data on TBI hospital discharges. Now, as the Program works to link data across agencies, its are trying to answer the question “then what?”. The Program continues to consider what should happen after persons with TBI are discharged from the hospital.

Working with data from various policy and service worlds is difficult but very important. The Minnesota Program is heartened by both its and other States’ preliminary efforts but there is much left to do.

Develop a good staff. A dedicated unit that works well across divisions and among agencies specific to TBI services coordination is critical. During 1990 to 1997, DHS TBI Program staff exerted focused and coordinated effort. Reorganization brought about dismantling of the Program, with various staff having responsibilities across disabilities. Staff was assigned to coordinate specific policy and services such as the TBI waiver. Eliminated was the ability/responsibility to work across departments with a specific TBI focus. In the previous sense, the TBI “glue” and effort no longer exist.

Admission screening for persons admitted to State RTCs. This screening is one of the Program’s “two steps forward and one step back.” Though implemented as a policy and procedure in 1993 (with efforts made to collect/analyze data), the screening has never been fully implemented. So, the data analysis is less than complete. Additionally, the system is changing. State facilities are closing. Currently, there is discussion about screening “at risk” populations at various points in the systems, rather than just upon

admission to a State facility. Case finding is the only way to match persons in the systems with the most appropriate services. Additionally, data is necessary to convince decision makers of the need to build brain injury capacity into the various systems. The Program is not asking systems to take on new people to serve, rather it is expecting them to do better (to be more effective, more efficient) with the people they already serve.

The Minnesota TBI Interagency Leadership Council has worked. Formalizing the informal collaboration the Program enjoyed for years was an important step to developing the initial HRSA Federal TBI Program State Agency implementation grant. Having leaders and policy specialists in key State Agencies, along with the BIA of Minnesota, the TBI Protection and Advocacy System, the DHS TBI Advisory Committee representation, and others, to link together around planning policy and services is absolutely necessary. Other working partners include State Corrections, Vocational Rehabilitation, Special Education, and the Defense and Veteran's Regional Brain Injury Program.

Future program goals

The DHS TBI Advisory Committee, the MN TBI Interagency Leadership Council, and various policy staff and others are actively planning to address behavioral supports in a more cohesive manner. The Program intends to:

- Case find to better address identifying persons with brain injury “marbled through” various programs/services, perhaps with co-occurring disorders of mental illness or chemical dependency, or those who may be homeless and not connected to services (Minnesota’s 2003 Homeless Survey found 29 percent self-reported a TBI).
- Work with policy for and provision of behavioral supports, related to building capacity in systems and providers, to meet better the needs of persons with brain injury who may/may not have other co-occurring diagnoses. Case finding makes it possible to match up with appropriate services.
- Work hard to identify areas of promise and past progress upon which to build and improve.
- Connect without starting from scratch with screening for brain injury as a part of chemical health assessments at the county level.
- Guide workers to information resources, training, etc. to build capacity (in progress).
- Look at progress with specialized release planning for offenders with serious and persistent mental illness in our State Corrections facilities. Also, examine how to build staff capacity and support for offenders with TBI, patterned after the severe and persistent mental illness effort.
- Build upon the resource facilitation system, developed through HRSA’s Federal TBI Program State Agency Grants, now funded in Statute for persons leaving acute care hospitals with diagnosis of brain injury. Follow people to guide them better with information and connect them to services toward preventing secondary conditions/disabilities.

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DHS is the lead State Agency for TBI in Minnesota.

Minnesota Medicaid services information (e.g., TBI waiver, Personal Care, and the Rehabilitation Option/Adult Rehabilitative Mental Health Services) is available through the Minnesota Department of Human Services (www.dhs.state.mn.us).

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The New Hampshire Experience

Circumstances leading to development of the program

In 1997, HRSA's Maternal and Child Health Bureau awarded a TBI State Agency planning grant to the State of New Hampshire to conduct a comprehensive needs and resources assessment for brain injury services. In October 1999 *Brain Injury: The Time Has Come* was published as a collaborative effort of the New Hampshire Division of Developmental Services (NHDDS), the Brain Injury Association of New Hampshire (BIANH), and the TBI Planning Grant Advisory Board. The report set forth results of the needs assessment.

Several priority concerns emerged and were reflected in the New Hampshire Action Plan for Brain Injury:

- Problems in the neurobehavioral domain (mood, emotions, behavior, and cognition) are a major challenge to the majority of individuals with TBI and family/caregivers.
- These neurobehavioral consequences (NBC) are a source of enormous distress and excess disability, often underlying challenges in other areas such as return-to-work, school, and community.
- Individuals with TBI, family/caregivers, and providers all perceive that there is insufficient help available for NBC both in terms of amount of expertise available and basic access.

Similar to other States, New Hampshire's services for individuals with brain injury are provided through a large number of agencies and funding sources, with no one agency having sole responsibility for service provision. Availability of trained, appropriate providers was a critical issue, especially in rural areas. Even when funding was available and timely, services often were not. Services available in New Hampshire are both institutional (e.g., acute care hospitals, acute rehabilitation hospitals, nursing homes and acute psychiatric settings) and community-based (e.g., community mental health centers, the acquired brain disorder home and community-based care (HCBC) waiver, developmental disability HCBC waiver, elderly and chronically ill HCBC waiver, and NH Medicaid State plan services). Additionally, a number of not-for-profit organizations (e.g., the Brain Injury Association of New Hampshire and Krempels Brain Injury Foundation) play critical roles in offering services to individuals with brain injury and their families. Again, such services often lack appropriate care coordination and providers and agencies frequently lack the skills and expertise to manage TBI, especially its neurobehavioral consequences.

These were the priorities addressed by Project RESPONSE, as funded through a Maternal and Child Health TBI implementation grant. Project RESPONSE has made several major contributions, including the development of a model to increase expertise of community agencies in assessing and treating individuals with TBI-related NBC. It is unique in directly addressing the delivery of neuropsychiatric and related services to TBI individuals/families.

Goals and objectives of Project RESPONSE

The overarching mission of Project RESPONSE was “To improve New Hampshire’s capacity to assist people with neurobehavioral consequences of TBI.” Several specific goals were identified.

The first goal of Project RESPONSE was to enhance the level of provider expertise in the evaluation and management of TBI-related NBC, and to improve access to these providers. In the New Hampshire tradition, local control was identified as an essential element and, as a result, it was determined that local teams would be developed and trained to provide services/consultation around issues of TBI-related NBC.

The New Hampshire Bureau of Developmental Services and Bureau of Behavioral Health provide services through a regional system of area agencies and community mental health centers. Community-based waiver services for individuals with acquired brain disorders are provided through the Division of Developmental Services. For service purposes, the State has been divided into regions. There are twelve regional area agencies and ten regional mental health centers. To encourage cooperation between local area agencies and mental health centers, interagency teams were developed to discuss individuals whose needs were served by both agencies. These teams were chosen to train and provide consultation at a local level. Six interagency teams were chosen as pilot sites for Project RESPONSE, representing both urban and rural regions statewide.

The first step in the process was the development of a statewide, mobile resource/consultation team to provide training and consultation to local teams in the evaluation and management of TBI-related NBC. The team consisted of a neuropsychiatrist, a pediatric psychiatrist, a neuropsychologist, a behavioral psychologist, case managers and individuals knowledgeable about State and local resources. An individual with traumatic brain injury also served on the Project RESPONSE team to provide feedback, offer ideas, and contribute first-hand information about her recovery. Once the State team was developed, interested regions were required to make an application request. Six pilot sites were selected and trained over the next three years. To increase availability of services through the behavioral health system, waivers were developed for those pilot site mental health centers, allowing entry into the system for individuals with TBI who otherwise might not be eligible (due to lack of an appropriate Axis I diagnosis).

Capacity development to serve individuals with TBI-related NBC was first approached through a series of intensive statewide training, followed by case consultations with the State team. Statewide trainings were developed and implemented to provide intensive training in neurobehavioral consequences of TBI. Some of these trainings included: Neuropsychiatric Aspects of TBI; Project Response: The Consultation and Mentoring Process; Neuropsychiatric Aspects of TBI Across the Lifespan: Children, Adults, and Older Adults; Psychiatric Disorders Associated with TBI; Cognitive Sequelae: Assessment and Implications; Strategies for Helping Individuals with Cognitive

Impairments; Lack of Awareness of Deficits in Traumatic Brain Injury; Psychopharmacological Issues in the Management of Neurobehavioral Sequelae of TBI; Strategies for Helping Individuals with Behavioral Impairments; The Basics of Behavioral Interventions: Weaving Behavioral Momentum Into Everyday Life; and How to Modify Treatment When Your Client has Neuropsychological Deficits. These trainings occurred over the three-year life of the grant.

After initial statewide trainings, a series of client-specific consultations were conducted with each local interagency group. Prior to each consultation, the local team was required to fill out an extensive questionnaire identifying: reason for referral, pre-injury functioning and history, family history, medical history, current medications, previous medications, neurobehavioral symptoms, current life situation, level of functioning, as well as prior interventions and potential solutions.

The consultation model utilized role modeling and mentorship and incorporated a “see one, do one, teach one” model. Each consultation consisted of an initial interview with an individual and his or her family and/or significant other. A team meeting then followed to discuss the findings of the interview, integrate information provided into the medical records and referral questionnaire, and develop a set of appropriate recommendations. All consultations were conducted with the State and local teams in attendance. The first consultation with the local team involved primarily the State team conducting the team meeting. This meeting consisted of client, family, and service provider interviews, as well as a post-interview discussion. It resulted in development of recommendations and the writing of a report. With each subsequent consultation, the responsibility for conducting the interview, running the team meeting, developing the recommendations, and report writing gradually shifted to the local team, with back-up and feedback provided by the State team as needed. Following initial consultation with each client, quarterly mentoring meetings were held. The State team was also available for phone consultation as needed for discipline-specific, peer supervision. As a result of the work conducted during Project RESPONSE, New Hampshire now has six local interagency teams that are better equipped to provide services to their clients with TBI-related NBC.

The second goal of Project RESPONSE was to enhance the capacity of individuals with TBI and family caregivers to self-manage neurobehavioral challenges associated with TBI. This goal was difficult to achieve for a number of reasons, with only initial inroads made. To begin, local teams identified key service providers and support groups in their area. Additionally, each pilot site developed and held a local conference for local providers, individuals with traumatic brain injury, family members, and significant others. These conferences covered general issues related to the sequelae of TBI and an overview of how to access and use community resources. Development of connections and networks (between local agencies/providers/individuals/families) was essential to the success of these local conferences. The conferences were well attended and feedback was positive. Presentations by individuals and family members affected by TBI were consistently the highest rated aspects of the conference, having the greatest impact on attendees.

The goal of enhancing the capacity of individuals with TBI and family caregivers to self-manage was not unique to Project RESPONSE. Our first planning grant needs assessment identified the need for care coordination and resource facilitation for individuals with TBI to help them navigate the maze of agencies and available services. At the same time that Project RESPONSE was implemented and as a result of advocacy by the Brain Injury Association of New Hampshire (BIANH), State funds became available to brain injury services through the New Hampshire legislature. The New Hampshire Brain and Spinal Cord Injury Advisory Council decided to use the funds to develop a capacity for care coordination throughout the State. The Resource Facilitation Program was established at BIANH. Utilizing five resource facilitators, New Hampshire now has statewide resource facilitation services for individuals with TBI.

Upon completion of the implementation grant, New Hampshire applied for and was awarded a Maternal and Child Health Bureau TBI post-demonstration grant. This worked to build on the efforts of Project RESPONSE by enhancing capacity of individuals with TBI and family/caregivers to self-manage neurobehavioral challenges associated with TBI. The post demonstration grant identified three primary goals:

1. To develop and implement an ongoing individual/family education program.
2. To create a statewide peer-to-peer and family-to-family mentoring program called “Connections.”
3. To develop a statewide program of Regional Resource Networks (RRNs) that assists individuals and families in identifying and accessing community supports, resources, assistance, and information.

Through this grant, the State in collaboration with the Brain Injury Association of New Hampshire has maintained an ongoing individual/family education series. It has presented on a monthly basis and has an active mentoring program linking trained individuals and families living with new brain injuries. Through the already established Resource Facilitation Program, the State’s resource facilitators have developed a network of local resources and supports and created local resource books which complement BIANH’s already existing statewide resource directory. The goal to incorporate this local resource directory into the BIANH Web site remains.

Lessons learned/words of wisdom

As noted above, Project RESPONSE was not successful in implementing all of its goals. In evaluating the project, we identified a number of lessons based on our contact with local teams and feedback from all involved (through both written evaluations and focus groups).

- **There is an ongoing need for State resources.** While teams felt they learned an enormous amount, they did not feel ready to serve as experts without backup at the State level. Staff turnover on local teams was and will no doubt continue to

be a frequent occurrence, and results in unevenly trained teams with a need for ongoing support.

- **More training of frontline and intake staff needs to occur.** Training of interagency team participants did not trickle down to these staff. Even with development of the Acquired Brain Disorder (ABD) Unit, there was still a sense there needed to be ongoing training coordinated at the State level for many different parts of the system.
- **There needs to be more flexibility in consultations with the State team in discussing individuals.** Some teams found the length of the consultation form, the information gathering, and the report-writing requirements rather burdensome. There were many clients who did not want to meet with a large group of people. There were also concerns about behavioral dyscontrol in this kind of setting. Some people believed the large group size could be intimidating. Others thought it gave an opportunity for sharing many opinions. Flexibility in trainings was mentioned as well, with interest in having some of the trainings be elective (such as the tracks at the BIANH conferences).
- **Participation by individuals and family members in all phases of the project is critically important for the quality of training and project outcomes.** Presentations by individuals living with brain injury were consistently the highest rated part of training events and retreats. The Project consultant, who has a brain injury, was an excellent resource for the team. Participants with brain injuries at the advisory group level helped ensure that decisions regarding future planning were relevant to the needs of others with brain injuries.
- **Eligibility criteria, for both mental health and area agency services, need to take into account the needs of people with TBI.** In the area agency system, services are primarily available through a Medicaid waiver (ABD), with the high bar of skilled nursing care excluding all but the most impaired individuals. In the community mental health system, small gains have been made with a waiver of eligibility requirements for individuals with certain psychiatric conditions related to TBI. Work needs to be done to ensure that individuals with significant impairment due to behavioral and emotional sequelae of TBI are able to access appropriate services through community mental health centers.
- **There needs to be more follow-through after local provider/support group conferences.** Local agencies saw a need for follow-up with annual conferences and developing support networks, and would have liked to participate in such offerings. Unfortunately, other responsibilities intruded. In most regions, follow-through was minimal.
- **Increase in awareness of participants highlights the fact that there are limited resources.** In response to a question about the greatest obstacles related to this work, one participant commented, “I think the lack of funding. Although

we get all this information and we have all this knowledge, and we know about the need, we do not have the funding to follow-through all the time and do something to actually change the situation.”

The State team also identified several additional issues worth highlighting.

Impact of limited local financial resources on project participation. Many local teams expressed interest in participating in Project RESPONSE but were unable to, due to financial pressures that made it impossible to free up staff time. One region agreed to participate and then had to drop out for this reason. We courted one of the largest urban regions in the State but were unable to get them to participate for similar reasons.

Difficulty engaging psychiatrists in project activities. In general, local team psychiatrists were initially the least enthusiastic team members. Although several team psychiatrists eventually became very engaged, and in fact enthusiastic about project participation (showing great growth in terms of knowledge/awareness of the impact of brain injury issues in their practice), psychiatrists from several of the other teams continued to show some degree of resistance. It is worth giving further thought to strategies and incentives that would improve psychiatrist participation.

Impact of State level administrative turnover. During duration of the grant, New Hampshire has had two governors, three commissioners of the Department of Health and Human Services, five Division of Behavioral Health directors, and two Division of Developmental Services directors. Each of these individuals has viewed the priority of brain injury services differently; the level of turnover highlights the need for institutionalized funding for brain injury services.

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The New York Experience

Circumstances leading to program development

When the TBI Waiver Program began in 1994, there was a big emphasis on repatriation of the 600 New York State citizens in out-of-State facilities at a cost of \$60 million annually (plus the emotional cost of isolating these individuals from family and familiar surroundings).

The Department of Health was given \$300,000 to administer the waiver and repatriation program during the first year. Resources were focused on Long Island, the Hudson Valley, and two projects covering all five boroughs of New York City where most of the individuals who had been in out-of-state facilities formerly resided. Regional Resource Development Specialists (RRDS) were responsible for all aspects of waiver administration and provider development. Because of limited funding, State employees associated with the waiver program were responsible for program administration in the remainder of the State without use of contractors.

In the first year, Program contractors reported that the greatest barrier to success was that a great majority of their constituents had serious neurobehavioral challenges. TBI Program administrators determined that additional resources and interventions were needed to ameliorate neurobehavioral challenges so the majority of individuals could live successfully in the community.

In the next fiscal year, the DOH secured additional funding in the amount of \$700,000 to set up seven new regional resource programs in Upstate and Western New York and to develop a statewide neurobehavioral resource project. It was developed and has been directed by Tim Feeney, Ph.D., since its inception. Mark Ylvisaker, Ph.D., has been a consultant to the project from the first days as well.

Strategies for enlisting support of top government staff/legislators

The Program has had to convince its budget people of the need for increases for both the RRDS and the Behavior contract a few times in the last 10 years, but that has not been too difficult because the outcomes and cost savings are good and the numbers of people served keeps increasing. The Program has kept legislators aware of its successes by inviting them to the Annual TBI Program Best Practice Conference and by keeping them informed of successes that have occurred among their constituents in crisis.

Key players

Pat Green-Gumson, New York State DOH TBI Home and Community-based Services (HCBS) Waiver Program; Bruce Rosen, NYS DOH TBI HCBS Waiver Program; Tim Feeney, Ph.D., Project Director, NY State Neurobehavioral Resource Project.

Program description

The New York State Neurobehavioral Resource Project (NRP) is designed to provide:

1) Technical assistance for programs providing services to individuals with brain injury and behavioral challenges. This includes screening and assessment of individuals requesting waiver services, interaction and support for court systems, ongoing work with individuals and program providers in development/refinement of intervention strategies, and collaboration with multiple service providers.

2) Ongoing training for service providers. Traditional in-service trainings throughout the State and the continuous upgrading of a "best practices" manual for service providers

3) Ongoing program development through an Apprenticeship Program that includes ongoing coaching supports to service providers in the everyday places where individuals with brain injury live and work. The goal is to provide continuous development and improvement of local expertise. Also, project staff members collaborate with other agencies (e.g., Office of Substance Abuse Services, Office of Mental Retardation, and Office of Mental Health) to promote seamless supports for individuals with brain injury and coexisting disabilities (an increasing percentage of individuals served by project staff) across all possible domains of service provision.

Successes

The NRP has successfully supported over 700 individuals with brain injury and challenging behaviors that remain in their communities. A recent review indicates that this reflects an 84 percent success rate in helping individuals with significant behavioral difficulties, many with co-existing disabilities, remain in their homes. It is also reflective of an annual cost savings of approximately \$13 million per year.

Lessons learned/words of wisdom

Experience shows that individuals with brain injury and significant behavioral challenges can be successfully supported in community settings—as long as needed supports are available when they are needed.

Future program goals

- To enhance and expand the Apprentice Program, in order to have experts available locally and regionally.
- To build expertise in each provider agency.

- To advance what is now a best practice of collaboration with other State Agencies: joint agency service of persons with TBI and multiple disabilities as standard practice.

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Part VI: Working Effectively in Key Service Delivery Systems

Working Effectively in the Mental Health System

The consequences of a brain injury can be devastating to an individual because of the physical, psychological, and social outcomes that follow. Studies have shown that individuals who receive a brain injury are at increased risk of psychiatric and psychological problems, regardless of the severity of the injury. Common problems include changes in personality, difficulty with emotional control and mood regulation, dysinhibition, anxiety, and depression. Studies suggest that one-third to one-half of persons who have sustained a brain injury have one or more indicators of a post-injury psychiatric disorder. Other studies show that a brain injury increases the risk of depressive disorders even decades after the injury.

The increased supervision and caregiving required of family members, coupled with changes in the personality of the injured person, frequently strain relationships and family systems to the breaking point. Given these difficulties, it is not unusual for people with brain injuries and their family members to seek assistance from mental health service providers. However, they frequently do not receive treatment or interventions which account for the impact of the brain injury. Many professionals in the mental health field have no training in or familiarity with brain injury and its manifestations. Cognitive impairments, such as attention deficits, impaired judgment, poor problem solving, and problems processing language, make it difficult for the individual with TBI to take advantage of typical therapeutic interventions. The phenomenon of “deficit unawareness” (i.e., the inability to recognize one’s own difficulties in cognition and performance) further complicates efforts to provide effective interventions. Consequently, individuals seeking help may be misdiagnosed and receive treatment that is inappropriate or ineffective.

Mental health practitioners, seeking to be effective in their efforts to help individuals with brain injuries and their families, must first identify the presence of the injury. Then they must adapt their interventions to the individual’s cognitive problems.

There are a variety of instruments available to screen individuals for the presence of a brain injury. If screening is positive for a brain injury, further assessment will be required to assure the development of adequate interventions. Two popular tools are the Amen Brain System Checklist¹¹ and Mount Sinai School of Medicine’s Brain Injury Screening Questionnaire¹².

To further assess the individual, it may be necessary to arrange for a neuropsychological evaluation. The purpose of this evaluation would be to identify the nature of the injury and its impact on the individual’s ability to think, reason, and function. Information from

¹¹ Accessed online at <http://www.associatedtherapists.com/forms/amenchecklist.pdf>, March 27, 2006.

¹² For more information, go to: http://www.mssm.edu/tbinet/resources/technical_screening.shtml.

a neuropsychological evaluation may be helpful in identifying needed adaptations to therapeutic interventions.

Additionally, it is important for the mental health practitioner to assess the individual's functional abilities prior to the injury. For example, persons with poor social skills or mood control prior to their injury will require skills instruction in addition to accommodations for them to understand and benefit from therapeutic interventions. Social and emotional issues are different for individuals who had adequate skills prior to their injury and lost them, than for those who have never mastered the skills.

Accommodations to therapeutic interventions may include:

- shortened counseling sessions, to accommodate for poor attention span and fatigue;
- avoidance of compound questions;
- use of open-ended questions, rather than yes or no questions;
- use of pictures or other visual cues, in addition to verbal explanations and responses;
- repetition of information within and across sessions; and
- inclusion of family members or caregivers, if approved by the individual.

Additionally, the mental health practitioner needs to be prepared for therapy to continue for a long period of time, because of the need to accommodate for memory and organizational problems caused by the brain injury.

Payment for neuropsychological evaluations and extended sessions can be obtained in some States from traumatic brain injury trust funds, vocational rehabilitation programs or other return to work services, Medicaid waiver programs, private insurance, or worker's compensation insurance.

Working Effectively in the Substance Abuse/Chemical Dependency System

The National Head Injury Foundation (now the Brain Injury Association of America) Task Force concluded in a 1988 summary report that substance abuse is a major factor in 50 to 70 percent of persons who sustain a traumatic brain injury (TBI).¹³ Studies suggest that individuals drinking or taking drugs at the time of injury experienced longer and more costly hospital stays, had increased agitation, poorer cognitive/functional outcomes, and increased regional brain atrophy.¹⁴ The effects of substance abuse on cognition can potentially compromise the recovery and rehabilitation as well as reintegration into family, work, and community of nearly two-thirds of individuals with TBI.¹⁵

As documented by Corrigan and Lamb-Hart, “there is growing evidence that persons with traumatic brain injury and substance abuse problems have significantly worse problems than persons with traumatic brain injury alone. Among patients with the most severe brain injuries, alcohol or other drug consumption declines in the immediate post-injury period; however, people tend to return to pre-injury levels of use by two years post-injury (Corrigan, Rust et al., 1995; Kreutzer, Witol et al., 1996; Corrigan, Smith-Knapp et al., 1998). Approximately 20 percent of persons, who abstained or were light drinkers pre-injury, become high volume users after (Corrigan, Rust et al., 1995). Persons with traumatic brain injury and substance abuse problems are less likely to be working (Sander, Kreutzer et al., 1996; Bogner, Corrigan et al., 1997), and have lower life satisfaction (Bogner, Corrigan et al., 1997).”¹⁴

Identifying individuals with TBI and substance abuse issues

John Corrigan, Ph.D., and Gary Lamb-Hart, who are both associated with the Ohio Valley Center for Brain Injury Prevention and Rehabilitation have spent a number of years researching and implementing best practices in substance abuse treatment for persons with brain injury. They recommend using these criteria to identify persons who may have sustained a brain injury among those who abuse substances:

(a) An injury requiring medical attention due to a blow to the head, the head having impact with another object (e.g., the ground, a windshield) or substantial shaking without impact. Medical attention may include hospitalization, emergency room care, doctor’s office visit, or team trainer. Also, ask if a person was injured but was not able or allowed to seek medical care, determine the number of incidents, age at which they occurred, causes of injury, and type of treatment.

¹³ National Head Injury Foundation Substance Abuse Task Force. White paper. Southborough, MA: National Head Injury Foundation, 1988.

¹⁴ McAllister, Thomas, M.D., *Neurobehavioral Issues Following TBI, Part II* (Radiocast), <http://www.nashia.org>.

¹⁵ Corrigan, JD and Lamb-Hart, GL. *Substance Abuse and Brain Injury*. Brain Injury Resource Foundation, <http://www.birf.info>.

(b) There is self-reported altered consciousness after the kind of injury described above. Short or long duration of confusion or disorientation, impaired memory, or loss of consciousness would meet this criterion as long as these mental states can be distinguished from the effects of substance intoxication. Having been diagnosed with a concussion implies the conditions of this criterion.

(c) There is evidence of changes affecting life functioning that develop after the kind of injury identified above. The individual may not attribute the change to the injury—this can be a clinical judgment. Causation may be implied even if the onset is several months after the injury. Areas for potential limitations in life functioning include:

- health status (e.g., headaches, seizures, fatigue, or balance problems);
- changes in emotional functioning (e.g., onset of depression, anxiety, or irritability);
- difficulties with mental activities (e.g., concentration, everyday memory, comprehension, calculations, problem solving, impulsivity, organization, or geographic orientation);
- interpersonal problems (e.g., difficulties with temper control, relationship problems);
- difficulties succeeding in productive activities (e.g., work or school performance); and
- impulsive or disinhibited behavior.

Best practices for treating individuals with TBI and concomitant substance abuse

As cited by Corrigan and Lamb-hart, “persons with traumatic brain injuries face several challenges when seeking treatment from substance abuse providers. Cognitive impairments may affect a person's learning style, making participation in didactic training and group interventions more difficult. Misinterpretation of memory problems as resistance to treatment can undermine a treatment relationship. Damage to the frontal lobes affects executive thinking skills and promotes socially inappropriate behavior. Environmental cues may not be perceived, creating consternation for fellow clients and staff. It is easy to interpret these behaviors as intentionally disruptive, particularly when the individual with a brain injury shows no visible signs of disability (Center for Substance Abuse Treatment, 1998).”¹⁴

Corrigan and Lamb-Hart offer the following practical suggestions to substance abuse treatment providers or other professionals working with persons with TBI.

The substance abuse provider should determine a person’s unique communication and learning styles.

- Ask how well the person reads and writes or evaluate via samples.
- Evaluate whether the individual is able to comprehend both written and spoken language.

- If someone is not able to speak (or speak easily), inquire as to alternate methods of expression (e.g., writing or gestures).
- Ask about and observe a person's attention span. Be attuned to whether attention seems to change in busy versus quiet environments.
- Ask about and observe a person's capacity for new learning. Inquire as to strengths and weaknesses or seek consultation to determine optimum approaches.

The substance abuse provider should assist the individual to compensate for a unique learning style.

- Modify written material to make it concise and to the point.
- Paraphrase concepts, use concrete examples, incorporate visual aids, or present an idea in more than one way.
- If it helps, allow the individual to take notes or at least write down key points for later review and recall.
- Encourage the use of a calendar or planner. If the treatment program includes a daily schedule, make sure a pocket version is kept for easy reference.
- Make sure homework assignments are written down.
- After group sessions, meet individually to review main points.
- Provide assistance with homework or worksheets. Allow more time, taking into account reading or writing abilities.
- Enlist family, friends or other service providers to reinforce goals.
- Do not take for granted that something learned in one situation will be generalized to another.
- Repeat, review, rehearse, repeat, review, and rehearse.

The substance abuse provider should provide direct feedback regarding inappropriate behaviors.

- Let a person know a behavior is inappropriate. Do not assume the individual knows and is choosing to do so anyway.
- Provide straightforward feedback about when and where behaviors are appropriate.
- Redirect marginal, unnecessary or excessive speech, including a predetermined signal method to use in groups.

The substance abuse provider should be cautious when making inferences about motivation based on observed behaviors.

- Do not presume that non-compliance arises from lack of motivation or resistance. Check it out.
- Understand that unawareness of deficits can arise as a result of specific damage to the brain and may not always be due to denial.
- Confrontation shuts down thinking and elicits rigidity. Learn to roll with resistance.

- Do not just discharge for non-compliance. Follow-up and find out why someone has no-showed or otherwise not followed through.

Acknowledgments

NASHIA gratefully acknowledges Dr. John Corrigan and Gary Lamb-Hart for their contributions to this section.

John D. Corrigan, Ph.D., is board certified in Rehabilitation Psychology and is a Professor in the Department of Physical Medicine and Rehabilitation at Ohio State University and Director of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation. He is the Project Director for the Ohio Regional Traumatic Brain Injury Model System, a multi-center, longitudinal research program funded by the National Institute on Disability and Rehabilitation Research. Dr. Corrigan directs the *TBI Network*, a program providing community-based treatment for substance abuse after brain injury. He serves on the Advisory Committee to the National Center on Injury Prevention and Control at the Centers for Disease Control and Prevention. He serves on editorial boards of leading journals in rehabilitation and has received local and national awards for his service and research in the field, including the Brain Injury Association of America's William Fields Caveness Award.

Gary L. Lamb-Hart, M.D. received a Master of Divinity degree from the Iliff School of Theology in Denver, CO. Gary is the Center Manager for the Ohio Valley Center for Brain Injury Prevention and Rehabilitation at Ohio State University and a Team Leader for the Center's efforts in substance abuse prevention and treatment following brain injury. He has been a chemical dependency professional in the State of Ohio since 1988. Gary makes presentations to a wide range of professionals, individuals with TBI and family members about the issues of substance abuse and brain injury throughout the United States and has co-authored several articles, a book chapter and materials on this subject.

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Working Effectively in the Criminal Justice System

As noted earlier, a traumatic brain injury can result in a number of cognitive, emotional, and behavioral changes for the affected individual. Cognitive changes may include difficulty concentrating, reasoning, problem solving, as well as impaired judgment – especially in the area of social interactions. Additionally, the individual may have increased difficulty exercising self-control and personal restraint. Left untreated, these impairments may generate or exacerbate behavior that presents a risk to the individual or others. Such behavior may include aggression, inappropriate sexual expression, shoplifting, illicit drug use, or other unacceptable acts, and can lead to an individual's arrest and incarceration.

Because a brain injury, with its resulting cognitive and emotional impairments, is often not visible, and therefore difficult to detect, the behavior of an individual with TBI within jail settings may be attributed to other causes. This may be especially true if the individual has a history of inappropriate or unacceptable behavior prior to the brain injury, or if the individual has no self-care deficits. There is reason to believe that incarcerated individuals are more likely to come from impoverished backgrounds, and are less likely to have received adequate health care or treatment prior to arrest, rendering the prior identification of a brain injury difficult, at best.

The problems arising from a brain injury which contributed to arrest and incarceration are likely to also have a negative impact on the individual's ability to adapt to jail or prison. This can increase the risk of harm to the inmate and others in a variety of ways. Failure to identify a brain injury may result in a failure to provide necessary health care. The lack of judgment and self-control can contribute to management problems for institutional staff, and can lead to even greater restrictions for the affected individual. It may also result in the isolation of an individual whose behavior is wrongly attributed to bad intent, rather than to an inability to perceive and navigate social situations skillfully.

These same problems often make reintegration into the community difficult upon release. Without adequate planning for the transition, an individual with a brain injury may be at increased risk for re-arrest and continued involvement with the criminal justice system.

A variety of strategies can be employed to protect the individual and the community when a legal offense has occurred. These strategies include both pre-trial and post-conviction efforts, in addition to appropriate management of individuals during incarceration. Jail diversion strategies would include the assignment of the offending individual to a course of rehabilitation, with oversight and monitoring by the court. (The report of the *Criminal Justice and Mental Health Consensus Project*, coordinated by the Council of State Governments, provides an excellent model of intervention at key points of an individual's involvement with the criminal justice system.) Critical to the success of any of these efforts is the identification of a brain injury when the individual first comes into contact with the criminal justice system.

To cope with the growing number of persons with disabilities in its criminal justice system, and to decrease the risk of harm to them and to others, Kentucky's General Assembly passed House Bill 157 in the 2004 legislative session. This bill creates a telephonic, behavioral health, jail triage system to screen jail prisoners for mental health, suicide, mental retardation, and acquired brain injury risk factors. It requires a written screening instrument be used upon a prisoner's admission to jail and a statewide telephone hotline use if an increased risk factor is identified. The system accommodates non-English speaking persons as well.

The initial screening is conducted by jail personnel, who can utilize a continuously available, toll-free telephonic, triage hotline staffed by a qualified mental health professional. Under some conditions, an on-site evaluation of the prisoner is conducted by a qualified mental health professional. Some individuals are diverted directly to mental health or other treatment facilities.

Following screening and assessment, protocols for managing the prisoner's housing, supervision, and care can reduce the identified risks of harm during incarceration. Jailers are required to use the triage system and to, at least, consider utilizing its recommended protocols. Further information about Kentucky's jail triage system may be obtained from the Kentucky Department of Mental Health and Mental Retardation.

Recognizing the presence of a disability, including a brain injury, is important to efforts to divert individuals from jail to treatment and to assure that those who remain incarcerated present the least risk to themselves and others.

Part VII: Appendices

Appendix A: Recommendations

Identification

Increased identification and awareness of neurobehavioral residuals is needed to drive service development tailored to these unique and intense needs.

Collaboration

Considering the scope of the problem (e.g., 80-90,000 will experience the onset of long-term disability as a result of TBI annually¹⁶), collaboration between all constituents is a requirement...not just a nice idea.

With the tightening of insurance coverage and limited access to public support, every single support dollar available is needed to scratch the surface of the TBI problem.

Professionals need to be responsive, work as a team, and advocate to identify cohesive approaches at both individual and systems levels.

Collaborative systems of service and support must be strengthened by real technological innovations that contribute to functional outcome in the lives of persons with TBI.

If brain injury services and supports are going to be integrated within existing systems (e.g., MR/DD, MH, Corrections, etc.), then applicable, detailed, and creative protocols are needed to orient and promote relevant practices within these systems.

Public/Legislative Awareness

The dollars available do not match the magnitude of the need. Therefore, a new, innovative, and pervasive plan is needed to promote public/legislative awareness of the long-term consequences of brain injury.

¹⁶ Langlois JA, Rutland-Brown W, Thomas KE. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta (GA): Centers for Disease Control and Prevention, NCIPC; 2004.

Appendix B: Suggested Resources

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Appendix C: NASHIA Neurobehavioral Health Committee Members

Thomas W. Brown, B.S., holds a degree in Sociology from the University of Iowa and has more than 13 years of experience in the field of brain injury in the role of State government employee, private provider, and family member of an individual with a brain injury. He is currently Bureau Chief of Disability and Violence Prevention for the Iowa Department of Public Health. In this position, he manages the Office of Disability and Health, supervises the Brain Injury Program and other disability and violence prevention programs, and works with various councils, commissions, task forces, and work groups at both the State and Federal level. Tom is the current Treasurer and previous Secretary of the Board of Directors of the National Association of State Head Injury Administrators and serves as Chair of its Neurobehavioral Health Committee. Prior to his current position, he managed the Iowa Department of Public Health's Brain Injury Program and was staff to Iowa's Advisory Council on Brain Injuries for four years. Prior to working in State government, he worked clinically in neurobehavioral rehabilitation and long-term care, and volunteered with and served on the Board of Directors of the Brain Injury Association of Iowa.

John Capuco, Psy.D., is a practicing neuropsychologist for 18 years, John holds a doctorate in clinical psychology from Florida Institute of Technology, having completed a clinical internship with emphasis on neuropsychology at the University Of Nebraska Medical Center. Dr. Capuco is currently the Administrator of Brain Injury Services at the Bureau of Developmental Services, New Hampshire Department of Health and Human Services. He oversees the Acquired Brain Disorder (ABD) program including the ABD Medicaid waiver and is Principal Investigator on Project RESPONSE, New Hampshire's TBI Post Demonstration Grant. Prior to his current position, he was a clinical neuropsychologist at the Easter Seal Society and Director of the Brain Injury Program at HealthSouth Rehabilitation Hospitals. He currently serves on advisory boards for the New Hampshire Housing Authority Nursing Home Transition Grant and the Disabilities Rights Center Protection and Advocacy grant. Dr. Capuco is a member of the New Hampshire State Olmstead group and is President of the National Association of State Head Injury Administrators.

Sharyl Helgeson, R.N., PHN, holds a Bachelor of Arts degree in Nursing from Metropolitan State University in St. Paul, MN. She is currently a mental health program consultant at the Minnesota Department of Human Services, providing TBI consultation for the Adult Mental Health Division. She also represents the agency on the Minnesota TBI Interagency Leadership Council. Sharyl's background is in mental health, post-acute rehabilitation and nursing facility nursing. Certified in psychiatric nursing at a generalist level for 10 years, she worked with individuals with TBI as a nurse in a specialized mental health program. Then she moved to a public policy position focusing on provision of Medicaid case management, TBI waiver, and personal care services enhancement to address the needs of individuals with cognitive and behavioral issues. Sharyl is a Regional Representative on the Board of Directors of the National Association of State Head Injury Administrators (NASHIA) and a member of NASHIA's TBI Technical Assistance Center's Steering Committee.

Martin J. (Marty) McMorrow, M.S., holds a degree in Behavior Analysis and Therapy from Southern Illinois University in Carbondale and is currently Director of National Business Development for the MENTOR Network. With over 30 years of experience in human services program design and delivery, he has written more than 60 professional papers, several books and training programs and made presentations to family, professional, and advocacy groups. Marty co-developed the social skills training program *Stacking the Deck*, the language training program *Looking for the Words*, and numerous other behavioral clinical interventions with his colleagues at the Department of Treatment Development, which was supported by the Illinois Department of Mental Health and Developmental Disabilities. He also designed, implemented, and evaluated the Personal Intervention Neurobehavioral Program at the Center for Comprehensive Services in Carbondale, Illinois (now a part of the MENTOR Network).

Cindy Murdock-Elliott, M.A., holds a degree in Clinical Psychology from Middle Tennessee State University and is Assistant Superintendent at the Tennessee Rehabilitation Center, Department of Human Services, Division of Rehabilitation Services. There, she is also director of the TBI program which she helped start. A licensed psychological examiner, Cindy has worked in the field of brain injury in both public and private sectors for 15 years. Her experience includes day treatment and neurobehavioral services. Cindy has served on the Board of Directors of the Brain Injury Association of Tennessee and is a past-president of the NASHIA Board of Directors. She has two extended family members who have sustained brain injuries.

Colleen Ryall, Ed.D., holds a Doctorate in Special Education from the University of Kentucky and a Master of Arts in Clinical Psychology from West Virginia University. She is currently Director of the Brain Injury Services Unit at the Department for Mental Health and Mental Retardation Services, Cabinet for Health Services in Kentucky. Colleen has over 20 years of experience in developing and providing community-based services including directing residential programs in Pennsylvania and Maryland and consulting throughout the State of Kentucky. She serves as Secretary to the Board of Directors of NASHIA.

Staff

Anne King holds a Bachelor of Arts in Sociology from Wake Forest University and is a Project Manager for the National Association of State Head Injury Administrators. She has 25 years of experience in the human services field. Prior to her position with NASHIA, she was involved with coordination of services, grant management, and funds allocation on behalf of persons with brain injury at the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services. Anne provides staff support to the Neurobehavioral Health Committee.

Appendix D: Glossary of Treatment Team Professionals

Behavioral Analyst. A behavior analyst is a graduate or certified (some States) professional trained in 1) functional assessment of behavior and 2) design of interventions to promote desired behavioral alternatives to problem behaviors. Behavior analysts may perform functional analysis/assessment of problem behaviors and work with a team to design, train, and evaluate clinical interventions. The behavior analyst is particularly interested and skilled in examining relations between social/environmental factors and human behavior.

Direct Care Staff. Direct care staff can spend large portions of their time in a position to make a difference in the lives of individuals with brain injury. It should be expected that paraprofessional or direct care staff have special training related to their work, especially in programs specifically designed to accommodate and treat significant neurobehavioral issues. Direct care basic training includes the understanding the fundamentals of brain injury, communication, interactional methods, proactive behavioral intervention, and risk prevention or management.

Neurologist. A neurologist is a board certified medical doctor or osteopath who has trained in the diagnosis and treatment of nervous system disorders, including diseases of the brain, spinal cord, nerves, and muscles. Neurologists perform examinations of the nerves of the head and neck, muscle strength and movement, balance, ambulation, reflexes, and sensation, memory, speech, language, and other cognitive abilities.

Neuropsychiatrist/Psychiatrist. Neuropsychiatry involves the interface area of psychiatry and neurology. This is a specialized medical discipline involving the behavioral or psychological difficulties associated with known or suspected neurological conditions. Neuropsychiatrists are trained to evaluate neurobehavioral complications including problems with mood regulation, impulse control, irritability or anger management, and psychosis. Behavioral effects of medications can be another area of expertise. When the services of a neuropsychiatrist are not available, a psychiatrist could be consulted to assist with the diagnosis and treatment of emotional issues or bona fide mental illness following brain injury.

Neuropsychologist/Psychologist. A clinical neuropsychologist has special expertise in the applied science of brain-behavior relationships. Clinical neuropsychologists use this expertise in the assessment, diagnosis, treatment, and rehabilitation of patients across the lifespan. The clinical neuropsychologist evaluates patients' neurocognitive, behavioral, and emotional strengths and weaknesses and their relationship to normal and abnormal central nervous system functioning. He or she also assists with planning and implementing intervention strategies to improve functioning. If the services of a neuropsychologist are not available, a psychologist could be contacted to furnish diagnostic, assessment, preventive, and therapeutic service to focus on helping individuals resolve problems.

Nurse. Registered, licensed practical and certified nurses can play a particularly important role in the treatment of neurobehavioral issues. The nurse can a) provide direct assistance and education related to healthy lifestyles, b) help determine the efficacy of particular medications on cognitive and behavioral functioning, and c) act as a liaison between the patient, team, and medical staff.

Occupational Therapist (OT). Occupational therapists are skilled professionals whose education includes the study of human growth and development with specific emphasis on the social, emotional, and physiological effects of illness and injury. Occupational therapists assist individuals with mentally, physically, developmentally, or emotionally disabling conditions to develop, recover, or maintain daily living and work skills. OTs can help their clients improve their basic motor functions and reasoning abilities as they work to compensate for permanent loss of function.¹⁷

Physiatrist. A physiatrist is a board certified medical doctor who focuses on restoring function. Physiatrists are specialists in the diagnosis and treatment of patients of all ages in three major areas of medical care: diagnosis and treatment of musculoskeletal injuries and pain syndromes, electrodiagnostic medicine, and rehabilitation of patients with severe impairments resulting from catastrophic events or neurologic disorders.¹⁸

Physical Therapist (PT). A physical therapist is a health professional who guides the patient in movement and exercise to restore or maintain their physical strength, mobility, and function. The physical therapist evaluates components of movement, including muscle strength, muscle tone, posture, coordination, endurance, and general mobility. They consider the patient's potential for functional movement including the ability to move in the bed, transfer and walk. They then design an individualized treatment plan to help the patient achieve functional independence.

Social Worker/Case Manager. The purpose of direct social work practice in health care is to enhance, promote, maintain, and restore the best possible social functioning of clients, families, and small groups when they are affected by actual or potential stress caused by illness, disability, or injury. Services provided may be preventive, developmental, or remedial in nature, depending on agency purpose, setting, and need.¹⁹ A social worker/case manager can help the individual with TBI/family assess individual needs, coordinate services, and make necessary referrals. They are often the pivotal professional who makes sure that other professionals involved in an individual's care communicate with each other.

Speech/Language Pathologist. A speech/language pathologist is a professional educated in the study of human communication, its development and disorders. By evaluating the speech, language, cognitive-communication, and swallowing skills of

¹⁷ American Occupational Therapy Association, <http://www.aota.org>.

¹⁸ Association of Academic Physiatrists, <http://www.phsiatry.org>.

¹⁹ Encyclopedia of Social Work, 19th Edition, NASW, 1996.

children and adults, the speech/language pathologist determines what communication or swallowing problems exist and the best way to treat them.

Vocational Rehabilitation Counselor. Vocational rehabilitation counselors help individuals deal with the personal, social, and occupational effects of disabilities. They confer with physicians, psychologists, occupational therapists and employers to evaluate the individual's strengths and limitations, and provide personal and vocational counseling. They also help to arrange for medical care, vocational training, and job placement. With input from the individual, the vocational rehabilitation counselor develops a rehabilitation program that often includes job skills training.